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The Impact of Sociodemographic Factors on Health-Related, Neuropsychological, and Psychosocial Functioning in Youth with Spina Bifida

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LOYOLA UNIVERSITY CHICAGO

THE IMPACT OF SOCIODEMOGRAPHIC FACTORS ON HEALTH-RELATED, NEUROPSYCHOLOGICAL, AND PSYCHOSOCIAL FUNCTIONING IN YOUTH WITH SPINA BIFIDA

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BY
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ABSTRACT

Objective: There is a lack of research on the impact of sociodemographic factors on youth with spina bifida (SB). This is concerning given the pervasive health disparities that exist in pediatric chronic illness groups. The aims of this study were to examine: (1) differences in health-related, neuropsychological, and psychosocial functioning among youth with SB based on sociodemographic risk; (2) cumulative risk as a predictor of youth outcomes, as moderated by age; (3) SB-related family stress as a mediator of the associations between sociodemographic/cumulative risk and youth outcomes, longitudinally. Methods: Participants (*M* age = 11.43, 53.6% female) were recruited as part of a larger, longitudinal study (Devine, Holmbeck et al., 2012). The study included questionnaire (parent-, teacher-, and youth- report), neuropsychological testing, and medical chart data on sociodemographic factors (e.g., parent education, income, health insurance) health-related (body mass index, urinary tract infections, sleep disturbances, pain, medical adherence), neuropsychological (attention problems, executive function problems, academic achievement), and psychosocial functioning (internalizing symptoms, externalizing symptoms, social adjustment, health-related quality of life). Data were collected at three time points, spaced two years apart. Results: Certain sociodemographic factors and their cumulative risk were more predictive of outcomes than others. Youth characterized by sociodemographic risk had higher pain, lower academic achievement, but also fewer UTIs and fewer attention and executive function problems. Age did not moderate the association between cumulative risk and outcomes. Sociodemographic risk and cumulative risk predicted *lower* SB-related family stress, which, in turn, predicted several outcomes. Conclusions: Examining a range of sociodemographic indicators is warranted. Sociodemographic risk is linked to poorer outcomes in some ways, whereas, in other ways, youth with SB who are characterized by sociodemographic risk have similar or better outcomes compared to youth not characterized by risk. Results have implications for delivering evidence-based, diversity-sensitive clinical care to youth with SB.

CHAPTER ONE

INTRODUCTION

Spina bifida (SB) is a complex, heterogeneous condition that impacts those affected with numerous challenges throughout the lifetime. While families of youth with SB have demonstrated significant resilience (e.g., Lennon, Klages, Amaro, Murray, & Holmbeck, 2015), they are also at risk for experiencing challenges in multiple domains (e.g., Holmbeck & Devine, 2010). Indeed, research has shown that youth with SB are at risk for experiencing poor health-related, neuropsychological, and psychosocial functioning, especially when compared to typically-developing youth (e.g., Dennis, Landry, Barnes, & Fletcher, 2006; Holmbeck et al., 2003; Liptak et al., 2015).

A considerable amount of research has sought to understand what factors and processes impact outcomes among youth with SB and their families. However, a review of the current research literature reveals that a relatively small number of studies have considered the impact of the broader ecological context, such as the impact of sociodemographic factors. The studies that have focused on this topic have found evidence suggesting that sociodemographic factors may put youth at risk for poor *health-related*, *neuropsychological*, and *psychosocial functioning*. For example, one study found that youth with SB without private insurance were more likely to be incontinent and have limited mobility (Schechter et al., 2015). Another study found that household income explained significant variance in overall cognitive functioning among youth with SB (Wohlfeiler, Macias, & Saylor, 2008). Finally, another study found that youth with SB from low socioeconomic status (SES) families had poorer psychosocial functioning compared to youth with SB from high SES families, or compared to typically-developing peers from both low and high SES families (Holmbeck et al., 2003). These results suggest that low-SES status and SB status may be additive risk factors for psychosocial adjustment difficulties (Holmbeck et al., 2003).

Nevertheless, a more comprehensive examination of how youth are impacted by sociodemographic factors is needed given the pervasive health disparities that exist in the United States and around the world (Braveman & Gottlieb, 2014). Health disparities include differences in the presence of disease, health outcomes, or access to care due to sociodemographic variables (Chen, Martin, & Matthews, 2006; USDHHS, 2001). The growing body of research on child health disparities is revealing robust associations between sociodemographic factors and health-related, neuropsychological, and psychosocial functioning in children and adolescents (Cheng, Goodman, & Committee on Pediatric Research, 2015). Understanding these relations early in life is important for both improving children's health and for understanding the origins of adult health disparities. The fields of child development, pediatrics, and pediatric psychology have called for high-quality empirical investigations into topics of diversity and health disparities among children and adolescents (AAP, 2010; Cheng et al., 2015; Lescano, Koinis-Mitchell, & McQuaid, 2016). And while certain sociodemographic factors place all youth at risk, vulnerable populations, such as those with a pediatric chronic illness like SB, are likely to be especially impacted (AAP, 2010).

Another reason why more research is needed to understand the impact of sociodemographic factors among youth with SB is the lack of clarity and consistency among conceptual and methodological approaches used in this area of research (Cheng et al., 2015). This is certainly the case with existing studies on youth with SB, many of which have examined a limited number of sociodemographic factors in isolation, and have failed to use analytic strategies to disentangle the effects of each individual sociodemographic factor. Fortunately, increasing attention has been given to the empirical challenges present in this area of research. This attention has resulted in guidelines created to support scholarly endeavors focused on sociodemographic factors (e.g., APATFSES, 2007; Cheng et al., 2015). The field has emphasized the importance of taking a more nuanced approach to the conceptualization and methodology of such research questions, as this is needed to inform policy and interventions that can affect change at both the systemic and individual level (AAP, 2009; Cheng et al., 2015).

Because the impact of sociodemographic factors on child outcomes unfolds through complex processes, various theoretical models have been proposed to test these pathways, many drawing on the bioecological model of human development (Bronfenbrenner, & Morris, 2006). One such model is the cumulative risk model, which has been proposed to understand how the *accumulation* of sociodemographic risks affects development (Evans, 2003). While cumulative risk has not been examined in a sample of youth with SB, studies of other pediatric health condition populations have found cumulative risk to be uniquely associated with child and parent outcomes (e.g., among youth with cancer; Bemis et al., 2015). Another theoretical model used to study the impact of sociodemographic factors is the family stress model, which posits that sociodemographic factors influence child development *indirectly* through parent and family functioning. This model has not been tested in youth with SB, but it has in other pediatric health condition populations; these studies have revealed evidence that various parent- and family-level variables mediate the association between sociodemographic factors and youth outcomes (e.g., among youth with Type 1 diabetes; Chan, Miller, & Chen, 2016; Drew et al., 2011; Lord et al., 2015). Both the cumulative risk model and the family stress model offer valuable frameworks for investigating not just *if* sociodemographic factors impact outcomes among youth with SB, but also *how*. Identifying the pathways and mechanisms though which sociodemographic factors impact youth outcomes is essential for identifying targets for intervention (Cheng et al., 2015).

The current study sought to expand upon the limited understanding of how sociodemographic factors are associated with *health-related*, *neuropsychological*, and *psychosocial functioning* among youth with SB. The ***first objective*** was to examine differences in health-related, neuropsychological, and psychosocial functioning between youth who *are* and *are not* characterized by *risk* across multiple sociodemographic factors (Figure 1). The ***second objective*** was to examine the *cumulative* effect of sociodemographic risk as a predictor of youth health-related, neuropsychological, and psychosocial functioning, as moderated by age (see Figure 2). The ***third objective*** was to examine *SB-related family stress* as a mediator of the association between sociodemographic factors and cumulative risk, and youth health-related, neuropsychological, and psychosocial functioning over time (see Figure 3).

The current study also aimed to address several methodological issues that exist in studies to date by including multiple methods and reporters, longitudinal data, sound analytic strategies, and examination of potential mediating and moderating processes that are supported by strong theoretical and conceptual frameworks. It is hoped that findings from the current study will inform future research questions, evidence-based interventions that are sensitive to issues of diversity, and local and national policies aimed at improving outcomes among youth with SB.

CHAPTER TWO

REVIEW OF THE RELEVANT LITERATURE

Overview of Spina Bifida

SB is a congenital malformation caused by the failed closure of the embryonic neural tube during the early stages of pregnancy, resulting in malformations of the spinal cord and cerebral cortex (Copp et al., 2015). It is one of the most common congenital birth defects in the United States (U.S.), occurring in roughly 3 out of every 10,000 live births (CDC, 2011; NBDPN, 2010; Parker et al., 2010). Each day in the U.S., approximately eight infants are born with SB (Spina Bifida Association, 2008), and in 2002, there were approximately 24,860 youth living with SB (Shin et al., 2010). Inadequate maternal folic consumption is the most well-established cause for the neural tube defect in SB (Copp et al., 2015). Genetic factors are also believed to be a primary cause, but few specific genes have been identified. Other risk factors include teratogens (e.g., valproic acid and carbamazepine), diabetes mellitus, and obesity (Agopian et al., 2013; Copp et al., 2015).

There are four types of SB, each varying in severity. The most common and severe form of SB is *myelomeningocele*, in which the spinal cord and nerves are exposed through the vertebral opening resulting in moderate to severe disability. In *meningocele*, spinal fluid and meninges protrude through the vertebral opening, but the spinal cord remains intact, resulting in less impairment. In *lipomemingocele* and other *closed neural tube defects*, a malformation of the fatty tissue is enclosed over part of the spine. Lastly, *occulta*, the mildest form often resulting in no impairment, occurs when there is a small gap in the spinal column but no open lesion or sac (CDC, 2015). The severity of SB varies and depends, in part, on the spinal lesion level, with higher level lesions typically resulting in more severe complications (Copp et al., 2015). SB is a heterogeneous condition, and individuals with SB face a multitude of health-related, neuropsychological, and psychosocial challenges throughout their lives.

Health-Related Functioning

There are numerous neurological and physical complications associated with SB. Neurological complications may include the Chiari II malformation and associated hydrocephalus, abnormalities of white matter, and strabismus (Liptak et al., 2015). The presence of hydrocephalus typically requires a ventriculoperitoneal shunt. Almost 100 percent of newborns with thoracic-level lesions require a shunt, whereas approximately 85 percent of those with a lumbar-level lesion and 70 percent of those with a sacral-level lesion require it (Copp et al., 2015). Constant monitoring is necessary to detect shunt malfunction or infection, which may require shunt repair or replacement surgeries, possibly resulting in secondary insults to the central nervous system (Fletcher & Brei, 2010; Sandler, 2004). In addition, individuals with SB may have seizure disorders and hearing and visual impairments (Liptak, Garver, & Dosa, 2013).

Gross motor, fine motor, and sensory functioning in individuals with SB often depends on the location of the spinal lesion, with higher lesions resulting in greater paralysis and poorer limb movement quality (Dennis et al., 2006; Lomax-Bream, Barnes, Copeland, Taylor, & Landry, 2007). Other orthopedic complications may include scoliosis, kyphosis, hip contractures, hip dislocation, spasticity, and congenital talipes equinovarus (club foot), all which may require orthopedic surgeries throughout the lifetime (Sandler, 2004). Individuals may demonstrate coordination disorder as well. Depending on the degree of difficulty with ambulation, individuals with SB may use assistive devices including orthotics, braces, crutches, and wheelchairs (Bisaro, Bidonde, Kane, Bergsma, & Musselman, 2015). Poor circulation and reduced sensation often leads to pressure injuries, requiring frequent skin checks to prevent infections.

Neurogenic bowel and bladder is common among individuals with SB, which may result in incontinence and urinary tract infections, requiring clean intermittent catheterization, medications, and possibly the wearing of diapers (Liptak et al., 2013). Renal damage and failure are among the most severe complications of SB, with reported death due to renal failure up to 20 percent in the first year of life (De Jong, Chrzan, Klin, & Dik, 2008). Individuals with SB may experience bowel incontinence or irregularity, requiring various interventions such as laxatives, dietary restrictions, nutritional supplements, and digital stimulation (Liptak et al., 2013).

Fortunately, advancements in technology and medical care have resulted in greater life expectancy for infants born with SB, with recent rates of survival to adulthood ranging from 75 to 85 percent in the U.S., compared to only 50 percent in 1980 (Gortmaker & Sappenfield, 1984; Liptak et al., 2015). Still, life expectancy for those with SB is still less than for the general population (Liptak et al., 2015). Further, individuals with SB are at increased risk for chronic health conditions such as cardiovascular disease, diabetes, obesity, and bladder cancer (Buffart et al., 2008; Cope et al., 2013; Husmann, 2009; Liptak et al., 2013), and health problems that begin in childhood tend to persist into later adulthood (Liptak et al., 2015).

The numerous neurological and physical complications associated with SB impact functioning in other domains (e.g., psychosocial functioning), and demand that individuals receive intense medical care throughout their lifetime. To maintain optimal health, individuals must follow a demanding medical regimen which can include doctor visits, surgeries, medications, use of assistive devices for mobility, skin checks, bowel and bladder programs, dietary restrictions, and physical and occupational therapies (Holmbeck, Zebracki, Papadakis, & Driscoll, 2017).

Neuropsychological Functioning

Deficits in neuropsychological functioning are common in individuals with SB (Dennis et al., 2006; Hetherington, Dennis, Barnes, Drake, & Gentili, 2006). Youth with SB and hydrocephalus often demonstrate poorer performance on neuropsychological tests, demonstrating average to low average cognitive capabilities, with relatively better performance on verbal than nonverbal tasks (Dennis et al., 2006; Riddle, Morton, Sampson, Vachha, & Adams, 2005; Wills, 1993). Specific deficits have emerged over many domains of neuropsychological functioning, including executive function, attention, memory, visuo-spatial processing, and visual-motor integration. Individuals with SB may also have learning disabilities (with weaknesses in math skills and reading comprehension) and intellectual disability (Copp et al., 2015; Dennis et al., 2006; Liptak et al., 2013).

Such deficits and disabilities may qualify youth and young adults with SB for special education services, such as an Individual Education Program or 504 Plan, and necessitate accommodations in the workplace (Johnson, Dudgeon, Kuehn, & Walker, 2007). Impaired neuropsychological functioning has been to shown to negatively impact areas of education, employment, mental health, personal relationships, and condition management and self-care (Lennon et al., 2015; Rose & Holmbeck, 2007, Tuminello, Holmbeck, & Olson, 2012).

Psychosocial Functioning

Along with numerous health-related and neuropsychological-related challenges, youth with SB are likely to face significant psychosocial challenges. Indeed, research has shown that these youth have poorer psychosocial outcomes compared to typically-developing youth (Ammerman et al., 1998; Holmbeck & Devine, 2010; Holmbeck et al., 2003, 2010; Rofail, Macguire, Kissner, Colligs, & Abetz-Webb, 2013).

Numerous studies have found that youth with SB are at risk for increased internalizing symptoms, particularly depressive symptoms, as well as lower levels of self-concept (Kabra, Feustal, & Kogan, 2015; Shields, Taylor, & Dodd, 2008). These rates are especially high when compared to their typically-developing peers (Cate, Kennedy, & Stevenson, 2002; Holmbeck et al., 2003; Holmbeck et al., 2010; Kelly et al., 2012). Youth with SB may also be at risk for externalizing symptoms, though the existing evidence is mixed (Ammerman et al., 1998). A meta-analytic review of 87 studies by Lavigne and Faier-Routman (1992) revealed that children with pediatric physical disorders, including SB, were at increased risk for externalizing symptoms. However, another study found no difference in externalizing symptoms between 8-9 year-olds with SB and their same-aged peers (Holmbeck et al., 2003). Given that youth who experience depressive symptoms during adolescence are more likely to exhibit recurrent episodes of depression throughout adulthood (Graber, 2004), and that internalizing and externalizing problems more generally can negatively impact one’s capacity to lead a healthy and productive life (Judd et al., 2000), research on factors that may contribute to psychological adjustment in youth with SB has direct implications for prevention and intervention.

Youth with SB are also at risk for experiencing social difficulties, which appear in childhood and persist throughout adolescence (Holmbeck et al., 2010). Specifically, youth with SB are less socially competent compared to their typically-developing peers, such that they tend to be more socially immature and passive, and demonstrate less adaptive social behaviors when interacting with peers (Holbein et al., 2015; Holmbeck et al., 2003; Shields et al., 2008). Youth with SB also report that they are less socially accepted, have fewer friendships, have smaller peer networks, spend less time with friends, and participate in less organized social activities (Blum, Resnick, Nelson, & St. Germaine, 1991; Buran, Sawin, Brie, & Fastenau, 2004; Cunningham, Thomas, & Warschausky, 2007; Devine, Holmbeck, Gayes, & Purnell, 2012; Ellerton, Stewart, Ritchie, & Hirth, 1996; Holmbeck et al., 2003; Holmbeck et al., 2010). Finally, compared to the friendships of their typically-developing peers, youth with SB tend to have friendships that are less likely to be reciprocated and are of poorer quality (i.e., lower levels of companionship, security, emotional support, and closeness; Cunningham et al., 2007; Devine, Holmbeck, et al., 2012). For example, youth with SB viewed their friendships as being closer than as rated by their friends, and were more likely to view their peers as best friends than their peers were to see youth with SB as best friends (Devine, Holmbeck, et al., 2012). Understanding more about social adjustment in youth with SB and what factors may impact it is important for youth's adjustment in its own right, and also because research has found adaptive social adjustment to be associated with better psychological adjustment (Guerra & Leidy, 2008; Kim & Cicchetti, 2004; Rubin, Chen, McDougall, Bowker, & McKinnon, 1995; Shonk & Cicchetti, 2001).

Lastly, research has found that youth with SB may be at risk for reduced health-related quality of life (HRQOL; Sawin & Bellin, 2010). HRQOL is characterized by several dimensions of a child’s health and well-being (e.g., physical, psychological, and social well-being; De Civita et al., 2005) and has been recognized as a key marker of health outcomes in pediatric populations (Eiser & Jenney, 2007). Past studies have found youth with SB to have lower HRQOL when compared to typically-developing populations (Bartonek, Saraste, & Danielsson, 2012; Murray et al., 2015; Parekh et al., 2006), a sample of youth with cerebral palsy (Okurowska-Zawada et al., 2011), and mixed samples of youth with chronic illnesses (Murray et al., 2015; Parekh et al., 2006).

Impact of Sociodemographic Factors on Youth with Spina Bifida

A substantial body of literature has documented that disparities in children’s health outcomes exist due to various sociodemographic factors, and these disparities have been found among typically-developing youth and youth with health conditions and disabilities (APATFSES, 2007; Berry, Bloom, Foley, & Palfrey, 2010; Cheng et al., 2015; Lescano et al., 2016). Pediatric health conditions shown to be negatively impacted by sociodemographic factors include cancer (Bemis et al., 2015), diabetes (Borschuck & Everheart, 2015), asthma (Chen, Fisher, Bacharier, & Strunk, 2003), HIV/AIDS (Coscia et al., 2001), obesity (Fradkin et al., 2015), as well as cystic fibrosis, cerebral palsy, sickle cell disease, hemophilia, and traumatic brain injury (Berry et al., 2010; Mullins et al., 2011). While it is clear that sociodemographic factors impact outcomes among pediatric populations, the impact is not the same across illness groups. For example, compromised access to care has been found to explain health disparities among youth with asthma but not in youth with cystic fibrosis (Schechter et al., 2015). Sociodemographic factors may affect prevalence rates, health care access and utilization, condition treatment and management, condition progression and outcomes, and numerous other physical and mental health outcomes (Berry et al., 2010). It is important to understand how sociodemographic factors may impact youth with SB, given the complex nature of the condition and the numerous health-related, neuropsychological, and psychosocial challenges that may confront these youth.

Prevalence Rates

One way that sociodemographic factors are clearly known to impact SB is through its incidence and prevalence rates. Indeed, the prevalence rates of SB differ based on socioeconomic status (SES) and ethnicity. One study found that compared to women with a high school education, those with less than a high school education had a 1.7-fold increased risk of delivering infants with a neural tube defect, and the risk increased to a 2.0-fold increased risk if they lived in a neighborhood where the majority of residents had not graduated from high school. However, no significant increases in risk were found based on neighborhood SES (Grewal, Carmichael, Song, & Shaw, 2009). Another study found that low SES was related to increased rates of several birth defects, including SB, and that the birth prevalence of SB was greater in families in which the father had a low SES occupation (e.g., operator/laborer; Yang et al, 2008).

Hispanics have the highest incidence rate of SB (4.2 per 10,000 live births), followed by non-Hispanic whites (3.2 per 10,000) and non-Hispanic African Americans (2.6 per 10,000; Boulet et al., 2008; Williams, Rasmussen, Flores, Kirby, & Edmonds, 2005). Latina women in the U.S., particularly Mexico-born women, have a two-fold higher risk of neural tube defect-affected pregnancies (Velie et al., 2006). A study using a large surveillance dataset showed no difference in rates of survival to 1 year of age among Hispanic infants with SB, compared with their non-Hispanic white counterparts (Bol, Collins, & Kirby, 2006). However, it appears that as youth with SB age, the prevalence rates become more consistent across groups, suggesting that Hispanic individuals with SB may have lower survival rates (Shin et al., 2010).

In 1992, the U.S. Public Health Service recommended that all women of childbearing age consume 400 mg of folic acid daily to help prevent pregnancies affected by neural tube defects such as SB. Subsequently, the Food and Drug Administration (FDA) mandated adding folic acid to all enriched cereal grain products by January 1998. Fortification is estimated to prevent approximately 1,000 pregnancies from neutral tube defects every year in the U.S. (Williams et al., 2015), and it has resulted in a decline in the prevalence of SB (Williams et al., 2005). The incidence of SB in the U.S. decreased 22.9 percent from 1995/1996 to 1998/1999. However, by 2004, no further decreases were observed. From the early post-fortification period of 1999/2000 to the recent post-fortification period of 2003-2005, the incidence of SB among non-Hispanic African Americans decreased 19.8 percent, but no significant decreases were found for Hispanics or non-Hispanic whites (CDC, 2009).

It has been suggested that prevalence rates are highest among Hispanics because of differences in folic acid consumption. While 30 percent of non-Hispanic white women report consuming at least 500 mg of folic acid daily, only 17 percent of Hispanic women reported the same (Tinker, Hamner, & Crider, 2014). As of April 2016, the FDA approved *voluntary* fortification of corn masa flour at the same level as enriched cereal grain products in an effort to increase folic acid consumption among Hispanic women (USFDA, 2016). In addition, genetic factors may also explain the high prevalence rate among Hispanics, because a genetic polymorphism commonly found in Hispanics has been linked with folate insufficiency (Crider et al., 2011).

Economic Burden

When considering how sociodemographic factors impact outcomes among youth with SB, it is important to consider the significant economic burdens placed on these families because of the lifelong intensive health care needs. Economic burdens may include out-of-pocket medical costs, transportation, special education, dvelopmental services, assistive technology, and lost wages (Yi, Lindermann, Colligs, & Snowball, 2011). The estimated lifetime cost related to SB is $600,000, with medical costs ranging from $285,959 to $378,000 (in 2010 dollars) and the remainder involving indirect costs (e.g., special education, assistive technology, caregiver support, loss of future earnings; Rofail et al., 2013; Yi et al., 2011). Individuals with SB with private health insurance are typically responsible for 8 percent of their inpatient care costs, 11 percent of their outpatient care costs, and 17 percent of their prescription drug costs, which in 2006 was $40,928 (Ouyang, Grosse, Armour, & Waitzman, 2007). Further, one study found an average reduction in weekly paid work time of 14 hours for mothers and 5 hours for fathers among families of youth with SB, and these differences in work hours translated into a lifetime cost of $162,124 in 2010 dollars (Tilford, Grosse, Goodman, & Li, 2009).

Health-related Outcomes

Few studies have examined the impact of sociodemographic factors on health-related outcomes among youth with SB. One study using a national registry dataset found that among youth and young adults with SB ages newborn to 22 year-olds, after controlling for SES, non-Hispanic African Americans with SB were more likely to have bladder and bowel incontinence, followed by Hispanics and then non-Hispanic whites. However, no associations were found between race/ethnicity and mobility status or the prevalence of pressure injuries. Further, compared to those with private insurance, those without private insurance were more likely to have bladder and bowel incontinence and pressure injuries (Schechter et al., 2015). Another study found that lower SES predicted greater sleep disturbances for adolescents with SB (Murray et al., 2016).

Neuropsychological Outcomes

Compared to the few studies examining health-related outcomes, there is more research documenting how sociodemographic factors put youth with SB at risk for poorer neuropsychological outcomes. It was found that lower SES was associated with poorer associative cognitive processes (Dennis et al., 2006), and that household income explained significant variance in overall cognitive functioning whereas both higher household income and maternal education predicted higher vocabulary scores (Wohlfeiler et al., 2008). Another study found that among individuals with SB ages 4 to 29 years, SES was the strongest predictor of vocabulary scores, whereas medical complications were more closely related to non-verbal cognitive outcomes (Bier, Morales, Liebling, Geddes, & Kim, 1997).

Importantly, two studies have highlighted that the presence of SB has an additional impact regardless of SES, suggesting that SB status and low-SES status may be additive or cumulative risk factors for poor neuropsychological functioning. Indeed, Lomax-Bream and colleagues (2007) found that among a sample of six to thirty-six month olds, lower SES predicted poorer cognitive and language skills in both those with and without SB. However, low SES children with SB had the slowest rates of growth in cognitive, language, and motor outcomes (Lomax-Bream et al., 2007). Another study found that youth with SB from low SES homes had the lowest scholastic competence and academic performance; however, receptive vocabulary skills accounted for a significant portion of the effect on scholastic functioning (Holmbeck et al., 2003).

Further, several studies have examined neuropsychological functioning specifically among Hispanic youth with SB. Fletcher and colleagues (2005) found poorer cognitive outcomes in Hispanic children with SB compared to non-Hispanic children. Another study found that Hispanic children with lower SES had lower verbal than nonverbal IQ scores, Hispanic children with higher SES and non-Hispanic white children demonstrated the reverse pattern, and these results did not vary for those children who completed tests in Spanish instead of English (Swartwout, Garnaat, Myszka, Fletcher, & Dennis, 2010). However, IQ scores were not related to access to educational opportunities, adequacy of available economic resources, or parents' educational aspirations for their children (Swartwout et al., 2010).

Psychosocial Outcomes

The majority of past studies examining psychosocial outcomes among youth with SB have included sociodemographic constructs as covariates, and not as primary explanatory variables. This limits our understanding of how psychosocial functioning is impacted by such sociodemographic factors, and warrants further research.

Studies that have investigated sociodemographic factors and psychosocial outcomes have primarily focused on social adjustment. One study found that, compared to non–Latino Caucasian youth with SB, Latino youth with SB were reported to be social competent (Papadakis et al., 2018). A camp-based intervention targeting independence among individuals with SB found that campers in the lower income group were reported to show greater improvement in social skills (Holbein et al., 2013). A study that examined social functioning among youth with

SB and a friend during a structured interaction task found that dyads of white youth were observed to show greater maturity, collaboration, and social dominance compared to mixed-race dyads (Holbein et al., 2015). Other research suggests that youth with SB participate in less diverse activities and to a lesser degree if they are from families reporting lower income, lower parent education, and single-parent status (Law et al., 2006). Further, those of Hispanic ethnicity or those from homes where English was not the primary spoken language are less likely to participate in social and work activities (Liptak, Kennedy, & Dosa, 2010). As with studies investigating neuropsychological outcomes, studies have found that SB- and SES-status may have cumulative impacts on social adjustment outcomes. For example, studies have found children with SB from low-SES homes had the fewest social contacts outside of school and were reported to have more social problems (Holmbeck et al., 2003), and that lower SES was associated with having fewer friends in youth with SB but not for a typically-developing comparison sample (Zukerman, Devine, & Holmbeck, 2011).

Other studies examining psychosocial outcomes have found that, compared to non–Latino Caucasian youth with SB, Latino youth with SB were reported to demonstrate fewer externalizing symptoms (Papadakis et al., 2018). In addition, Kulkarni and colleagues (2008) found that lower SES was related to poorer HRQOL among a sample of youth with SB.

Approaches to Studying Sociodemographic Impact

While research investigating the impact of sociodemographic factors on child health continues to grow, and evidence builds that these factors can explain a significant proportion of variance in child outcomes, the theoretical, conceptual, and methodological approaches to studying sociodemographic factors vary greatly from study to study. This inconsistency across studies poses a significant challenge to understanding mechanisms through which these relations occur, thereby hindering the development of interventions and policies that can help reduce or eliminate the negative impact of such factors at both the individual and societal level (AAP, 2009; Cheng et al., 2015). While it is recognized that testing competing theoretical models using different strategies is both appropriate and necessary, researchers across disciplines have called for their colleagues to strive for clarity and consensus in their conceptual and methodological approaches, and to take a more nuanced, yet comprehensive, approach to studying sociodemographic factors (Adler & Stewart, 2010; APATFSES, 2007; Braveman, Cubbin, Marchi, Ecerter, & Chaves, 2001; Cheng et al., 2015; Conger, Conger, & Martin, 2010; Diemer, Mistry, Wadsworth, Lopez, & Reimers, 2013; Shavers, 2007).

First, it is important to review the numerous constructs that could be conceptualized as sociodemographic factors. These may include the following: household income, income-to-needs ratio (i.e., annual family income divided by the federal poverty level for a family of the same size), hourly earnings, wealth and assets (general accumulation of economic resources), poverty status, welfare status, occupation, employment status, educational attainment, human capital (generally defined as the value of one's skills to the labor force; Duncan & Magnuson, 2001), access to resources, access to healthcare, healthcare insurance, race/ethnicity, immigrant status, language use, time in the U.S., school quality, distance from grocery stores, distance to healthcare facilities, and other characteristics of the neighborhood, county, state, or region (Cheng et al., 2015; Shavers, 2007).

Past research has categorized sociodemographic factors into various, often overlapping, dimensions such as individual versus societal/contextual, proximal versus distal, relative versus absolute, or subjective/perceived versus objective (Evans, 2004; Trentacosta et al., 2008). Frequently, the categorization of such factors in research has varied depending on the study's conceptual approach and objectives. For example, one study may use the term "proximal" as a label for individual characteristics (e.g., race/ethnicity) and "distal" as a label for contextual characteristics (e.g., distance to healthcare), whereas a different study may use "proximal" as a label for direct influences (e.g., conflict with a parent) and "distal" as a label for indirect influences (e.g., parental education). Regardless, there is consensus that consideration needs to be given to factors at multiple levels, because whereas individual and contextual sociodemographic characteristics tend to be correlated, each can exert independent effects (Grewal et al., 2009; Pickett & Pearl, 2001). For example, a child with low family SES can live in a community where the neighborhood SES is relatively higher, allowing her to receive benefits that may not be available if she lived in a low SES neighborhood (e.g., better schools, access to health clinics).

It must be emphasized that way sociodemographic factors are characterized as *risk* factors for adverse outcomes is largely *socially* and *contextually* determined; risk is largely *not* inherent to the factor itself. Further, these determinations vary based on the region/country and change over time (Cheng et al., 2015). For example, whether one's annual income puts them at "risk" depends entirely on the context in which they live (e.g., living in an affordable rural community versus an expensive metropolis). Or, not having a college degree in year 2000 may have put individuals at greater risk for finding financially adequate employment, compared to not having a college degree in 1980.

The sociodemographic factor that illustrates this point the clearest is the conceptualization of racial/ethnic minority status as being a "risk" factor. Although historically race has been viewed as a biological construct, it is now known to have biologic and social dimensions that change over time and vary across societies and cultures. There is a lot of emphasis and discussion on race in the U.S., whereas other societies place less emphasis on race and more on class or other characteristics (Cheng et al., 2015). The body of research exploring what mechanisms may explain health disparities among racial groups has identified racial prejudice and discrimination as particularly strong socially-based mechanisms. Evidence is growing that individual and institutional racial discrimination are social stressors that then influence the psychology, physiology, and health behaviors of individuals. For example, the "weathering" hypothesis suggests that health deterioration among African Americans is a consequence of cumulative social, political, and economic adversity and marginalization. (Geronimus, Hicken, Keen, & Bound, 2006).

Theoretical Approaches

The basic underlying tenet of research on sociodemographic factors and human development is that social conditions influence development across time (e.g., Evans, 2004). Most studies have drawn from ecological models of human development to guide their theoretical approach (Doan, Fuller-Rowell, & Evans, 2012; Trentacosta et al., 2008). The bioecological model of human development (Bronfenbrenner, & Morris, 2006) - a refined version of Bronfenbrenner's original ecological model (Bronfenbrenner, 1977; Bronfenbrenner & Morris, 1998) - provides a theoretical framework for understanding development over the life course through consideration of four processes and the dynamic, interactive associations among them: process, person, contexts, and time. *Process* is considered to be at the foundation of this model, and represents interactions between person and environment over time. These *processes* and their influences will vary as a function of *person's* characteristics, the immediate and remote *contexts*, and *time* (Bronfenbrenner, 2005; Bronfenbrenner & Morris, 2006). Because sociodemographic factors span various levels (e.g., individual versus societal) and contexts (e.g., home versus school) across time, and are dynamic and interact with one another (e.g., education can impact occupation), the bioecological model is an appropriate tool for conceptualizing how child outcomes are impacted by sociodemographic factors. Various theoretical and conceptual frameworks have been proposed and tested to extend and elaborate upon the bioecological model (Conger et al., 2010). Two such models will be discussed here.

Cumulative risk models. Cumulative risk models have been proposed to understand how the accumulation of sociodemographic risks across development impacts a variety of physical and mental health outcomes (Evans, 2003). First proposed by Rutter (1983), the cumulative risk model encompasses proximal and distal constructs of social and physical environments which are categorized into risk factors that have been dichotomized based on a statistical cutoff (e.g., bottom quartile) or conceptual category (e.g., one parent household) to represent either the presence or absence of risk. These risk factors are then summed to produce a cumulative risk score (Evans, 2003; Rutter, 1993; Sameroff, Seifer, & McDonough, 2004).

Previous research has examined a range of constructs as indices of cumulative risk, many of which overlap among conceptual categorizations, including socioeconomic factors (e.g., income-to-needs ratio, parental education), physical factors (e.g., pollution), and psychosocial factors (e.g., marital discord, family turmoil, exposure to violence, parental mental health).

While many past studies have included more distal, contextual/ecological factors as indices of cumulative risk, others have examined cumulative risk as being a combination of distal *and* proximal factors. It has been suggested that the former approach is preferable because it is more theoretically grounded and allows for the examination of proximal factors (e.g., overprotective parenting) as potential mediators or moderators of the associations between distal indices of risk (e.g., neighborhood dangerousness) and child outcomes (e.g., behavior problems; Trentacosta et al., 2008).

Some researchers have proposed that cumulative risk variables are better predictors of child outcomes than single, isolated risk factor variables, because cumulative risk more accurately reflects the natural covariation of many childhood risk factors that are often disproportionally allocated in society, such as among poor and ethnic minority groups (Doan et al., 2012; Evans, 2003; Evans, Kim, Ting, Tesher, & Shannis, 2007; Sameroff, 2000). Indeed, numerous studies have revealed associations between cumulative risk and child internalizing and externalizing problems, stress, allostatic load, and cardiovascular problems (Ackerman, Izard, Schoff, Youngstrom, & Kogos, 1999; Appleyard, Egeland, van Dulmen, & Sroufe, 2005; Atkinson et al., 2015; Blanz, Schmidt, & Esser, 1991; Evans, 2003; Evans & Kim, 2007; Evans et al., 2007; Jones, Forehand, Brody, & Armistad, 2002; Trentacosta et al., 2008). Further these studies have argued for the importance of assessing the *timing of cumulative risk* across development and how it impacts *outcomes* assessed at different times across development. For example, Atkinson and colleagues (2015) found that cumulative risk measured at ages 5/6, 12/13, and 19/20 years all predicted outcomes at ages 25/26, but cumulative risk measured at 5/6 was predictive of outcomes at 25/26 above and beyond risk accounted for at ages 12/13.

Application to pediatric populations. While cumulative risk has not been examined in a sample of youth with SB, it has in other pediatric health condition populations. For example, Bemis and colleagues (2015) found that among families of children with cancer, individual and cumulative sociodemographic risk measures were uniquely and positively correlated with child and parent stress and distress.

Family stress models. The original Family Stress Model posited that sociodemographic factors influence child development *indirectly* through the lives of parents (Conger & Elder, 1994). Specifically, the model posits a causal pathway where sociodemographic factors lead to economic pressure, which influences parental emotional/behavioral problems, which contributes to interparental conflict, which leads to harsh parenting behaviors, and this impacts child development (Conger & Donnellan, 2007). While many studies have found support for this model, a greater number of studies have tested variations of it that have included numerous parent- and family-level constructs (e.g., parental resourcefulness, family conflict) as both mediators and moderators (Belsky, Bell, Bradley, Stallard, & Stewart-Brown, 2007; Chen, Matthews, & Boyce, 2002; Conger et al., 2010; Doan et al., 2012; Evans et al., 2007; Trentacosta et al., 2008).

Application to pediatric populations. While no studies to date on youth with SB have used family stress models to explain how family-level factors mediate the association between sociodemographic factors and child outcomes, these models have been used in other pediatric health condition populations. For example, among youth with asthma, chronic family stress mediated the relation between low SES and inflammatory markers (Chen et al., 2003, 2006). Other research has found that in samples of youth with Type 1 diabetes, marital status and race/ethnicity indirectly impacted externalizing behaviors through parenting (Lord et al., 2015), family income indirectly impacted metabolic control through parental acceptance (Drew et al., 2011), and that the impact of early life SES on metabolic outcomes was moderated by family affect (Chan et al., 2016). Further, research on pediatric cancer patients suggest that when examining the impact of sociodemographic variables, assessing both general and disease-specific stress can be fruitful (Bemis et al., 2015).

Application to spina bifida. Using a family stress model to explain how sociodemographic factors impact outcomes among youth with SB may be particularly informative. First, past research has shown that numerous family-level variables are related to health-related, neuropsychological, and psychosocial outcomes among these youth (Bellin et al., 2010; Essner & Holmbeck, 2010; Friedman, Holmbeck, Jandasek, Zukerman, & Abad, 2004; Holmbeck, Johnson, et al., 2002; Wohlfeiler et al., 2008). Second, while families of youth with SB demonstrate disruption in some domains but resilience in others at the family- level (Coakley, Holmbeck, Friedman, Greenly, & Thill, 2002; Jandasek, Holmbeck, DeLucia, Zebracki, & Friedman, 2009; Lennon et al., 2015), families are still at risk compared to families of typically-developing youth, especially if from low SES backgrounds. Specifically, compared to families of typically-developing youth, families of children with SB tend to display lower levels of cohesion during preadolescence, and families from lower SES backgrounds are particularly at-risk (Holmbeck, Coakley, Hommeyer, Shapera, & Westhoven, 2002). However, families do not demonstrate increases in family conflict as a function of pubertal development as is seen in families of typically-developing youth (Coakley et al., 2002), and some studies have found that overall levels of family stress (as measured by experience of stressful life events) were similar between groups (Holmbeck, Coakley, et al., 2002; Jandasek et al., 2009). Third, research examining the impact of family-level variables on youth outcomes has found differences based on ethnicity. Specifically, Papadakis and colleagues (2018) found the following: Latino families were observed to demonstrate less family conflict compared to non–Latino Caucasian families, greater family conflict predicted poorer friendship quality for Latino youth and *fewer* internalizing symptoms for non-Latino Caucasian youth, greater family cohesion predicted greater peer acceptance for non-Latino Caucasian youth, and family stress predicted greater internalizing symptoms for non-Latino Caucasian youth. Lastly, previous studies have not examined the impacts of disease-specific (or SB-related) family stress.

Methodological Approaches

Across studies there is significant variability in how sociodemographic factors are defined, measured, and analyzed. Often a variety of terms may be used to describe identical or similar constructs (Cheng et al., 2015; Shavers, 2007). For example, social class, class, stratification, socioeconomic status, and socioeconomic position are all terms that are used to refer to the same core construct. Importantly, identical constructs may have different operational definitions or may be measured differently. For example, SES is sometimes measured as a composite of parental education and occupation, which may also include income within the composite; income may be measured as the sum of parental monthly income or as the yearly household income-to-needs ratio; parental education may be measured as a continuous variable (e.g., years of education completed) or a categorical variable (e.g., completion or non-completion of high school). Furthermore, while the use of composite variables like SES is appropriate given the multidimensional nature of such constructs, attempts at unpacking composites also yield meaningful results that can identify specific targets for intervention or policy development (Cirino et al., 2002; Duncan & Magnuson, 2001). For example, some attempts at unpacking SES have found that most of the variance in outcomes is attributable to parental education and not parental occupation (Bradley & Corwyn, 2002; Swartwout et al., 2010).

Often, reliable data on sociodemographic factors may be missing, either due to the study's design (e.g., measures on income were not included) or due to participants' non-response (e.g., participants' unwillingness to disclose their income). In those cases, researchers may rely on proxy measures. For example, Schechter and colleagues (2015) analyzed data from the National SB Patient Registry. They examined participant insurance status as a proxy measure of SES because the registry did not contain information on other potential indicators such as family income, zip code of residence, parental education, or parental occupation (Schechter et al., 2015).

Lastly, there are various analytic strategies used to examine sociodemographic factors, some more appropriate than others. Often sociodemographic variables may only be examined as control variables or covariates, instead of as key independent, mediating, or moderating variables. These types of analyses do not yield results that can fully capture the dynamic associations among study variables (Diemer et al., 2013; Evans, 2004). In addition, sociodemographic factors are frequently examined in isolation and not within multivariate analyses or in comparison to each other, indicating that variance explained by related constructs is not taken into account (Cheng et al., 2015). This happens frequently with race/ethnicity and SES. For example, without accounting for potentially confounding constructs, differences between racial/ethnic groups are often interpreted as reflecting either cultural differences or inherent biological differences (Braveman et al., 2001). Some scholars argue that there is sufficient evidence that race/ethnicity and SES have independent effects on outcomes, so each should be controlled when examining the other (Shavers, 2007). In contrast, other scholars argue that SES in the U.S. is commonly a consequence of race/ethnicity, and the interaction between race/ethnicity and SES is so complex that even sophisticated analyses are unable to fully disentangle the independent effects of each (Shavers, 2007). Further, some studies have shown that SES has a different meaning across race/ethnic, gender, and age groups, and thus only multivariate analyses stratified by these variables are appropriate (Bravemen et al., 2005). For example, a 50-year-old who holds a low-SES occupation may be at greater risk than an 18-year-old who holds a similar position. The stratification approach is supported by studies that have found, for example, that income and education do not predict health outcomes as consistently among Latino immigrants in the U.S. as is the case among other groups (Braveman & Gottlieb, 2014), or that lower parental education is associated with poorer child health for Caucasian and African American children, but not for Hispanic and Asian children (Chen et al., 2006).

Rationale for the Current Study

SB is a complex, heterogeneous condition that requires intense lifelong medical care. Not only does it confront youth with health-related, neuropsychological, and psychosocial challenges throughout their lives, it also affects parents, siblings, and the family unit. While families have demonstrated significant resilience when faced with these challenges (e.g., Lennon et al., 2015), they continue to be at risk across multiple domains (e.g., Holmbeck & Devine, 2010).

Past research has sought to understand what factors and processes are associated with outcomes among youth with SB. However, a review of the current research literature reveals a dearth of studies attempting to understand how sociodemographic factors impact this population. This critical gap in the literature is problematic, considering how pervasive health disparities are in the U.S. and around the world (Braveman & Gottlieb, 2014). There is no question that human development is shaped by social determinants from conception to death, but the ever-growing body of research on disparities is revealing robust associations between sociodemographic factors and health-related, neuropsychological, and psychosocial functioning (Cheng et al., 2015). The fields of child development, pediatrics, and pediatric psychology have called for more high-quality empirical investigations into topics of diversity and health disparities among children and adolescents (AAP, 2010; Cheng et al., 2015; Lescano et al., 2016). And while certain sociodemographic factors place all youth at risk, vulnerable populations, such as those with a pediatric chronic illness like SB, are likely to be especially impacted (AAP, 2010). Indeed, the limited research on this topic among those with SB has found just that. For example, Lomax-Bream and colleagues (2007) found that low SES children with SB had the slowest rates of growth in developmental outcomes when compared with low SES children without SB and all high SES children.

More empirically rigorous research is needed to support the development of effective policies aimed at addressing disparities related to sociodemographic factors, as policies require continuous evaluation and refinement. For example, Kulkarni et al. (2008) studied a sample of Canadian families of children with SB and found that, despite universal health care coverage in Canada, children from low-income families and families with lower parental education had poorer overall health and cognitive outcomes. The authors of this study suggested that, although the Canadian health care system removes financial barriers to accessing primary medical care and any necessary tertiary medical care (including surgery, hospitalizations, and diagnostic imaging), some medical costs are not covered, including prescription medications, dental care, some rehabilitation therapy services, and some travel costs to tertiary centers, which can be substantial for those living in remote communities (Kulkarni et al., 2008).

Research on the impact of sociodemographic factors involves a complex array of dynamic, causal processes and pathways that unfold over long time periods. The lack of clarity and consistency among conceptual and methodological approaches used in this research has often left more questions than answers (Cheng et al., 2015). This is certainly the case with existing studies on youth with SB, many of which use a limited number of sociodemographic factors and fail to use analytic strategies to disentangle the effects of each. Fortunately, increasing attention has been given to the empirical challenges that arise in this area of research. This attention has resulted in guidelines created to support scholarly endeavors focused on socioeconomic factors (e.g., Report of the APA Task Force on Socioeconomic Status; APATFSES, 2007; Cheng et al., 2015).

Review of the current research literature also highlights promising models for identifying mechanisms through which sociodemographic factors impact youth outcomes (Conger et al., 2010). Identification of such mechanisms is essential for identifying targets for prevention and intervention (Cheng et al., 2015). This is because most sociodemographic factors, such as family income or immigrant status, cannot be modified by interventions; thus, the processes through which such factors influence outcomes must be identified and addressed (Duncan & Magnuson, 2001). Before interventions are developed, documenting specific disparities, and the mechanisms through which they impact child outcomes, can both identify subgroups of youth who are particularly at risk for poor outcomes and inform the care and treatment provided by medical and education professionals (Berry et al., 2010).

The Current Study

The current study sought to expand our limited understanding of how sociodemographic factors impact health-related, neuropsychological, and psychosocial functioning among youth with SB, through the causal pathway of SB-related family stress. It is hoped that findings from this study will inform future research questions, evidence-based interventions that are sensitive to issues of diversity, and local and national policies aimed at improving outcomes in this population.

The current study also sought to address several methodological issues that exist in studies to date on the impact of sociodemographic factors in youth with SB. Current research is limited by the use of single methods and single reporters. Using multiple methods and reporters has been encouraged within research in general, and the field of SB research specifically (Holmbeck, Greenley, Coakley, Greco, & Hagstrom, 2006). In addition, the use of single sociodemographic factors in isolation or exclusively as covariates is a weakness of current research in this area. It is recommended that multiple factors be included in multivariate analyses to disentangle competing effects (Cheng et al., 2015). Further, research that seeks to better understand how sociodemographic factors impact youth with SB will be enhanced if it is firmly grounded within a developmental framework (Chen et al., 2002; Holmbeck et al., 2006). One way to establish a developmental framework is to examine these processes over time using longitudinal data. Indeed, it has been recommended that research being conducted on both sociodemographic factors and functioning in youth with SB use longitudinal moderation and mediation research designs to assess processes and outcomes over time (Chen et al., 2006; Holmbeck et al., 2006; Holmbeck & Devine, 2010). By studying the relation between sociodemographic factors and youth functioning over time, findings can reveal not only *whether* differences exist between particular samples of youth with SB, but also *why* they exist (e.g., due to meditating or moderating processes). Thus, this study sought to address the aforementioned methodological limitations by including multiple methods and reporters, sound analytic strategies, longitudinal data, and a design that included moderation and mediation factors that are founded on strong theoretical and conceptual frameworks.

Study Hypotheses

The present study sought to understand associations between sociodemographic factors and health-related, neuropsychological, and psychosocial functioning among youth with SB. *Sociodemographic factors* included youth race/ethnicity, youth health insurance, parent education, parent employment status, parent occupation, parent immigrant status, parent language, family structure, family income, and zip code income. *Health-related functioning* was assessed through examination of BMI, sleep disturbances, number of lifetime UTIs, pain, and medical adherence. *Neuropsychological functioning* was assessed through examination of attention problems, executive function problems, and academic achievement. Finally, *psychosocial functioning* was assessed through examination of internalizing symptoms, externalizing symptoms, social adjustment, and HRQOL.

The ***first objective*** was to examine differences in health-related, neuropsychological, and psychosocial functioning between youth who *are* and *are not* characterized by *risk* for each sociodemographic factor, all at Time 1. It was hypothesized that, compared to youth *not* characterized by sociodemographic risk, those who are characterized by sociodemographic risk will demonstrate poorer health-related, neuropsychological, and psychosocial functioning (see Figure 1).

Figure 1. Study Variables

Sociodemographic Factors

- Youth Race/Ethnicity
  - *Non-Risk:* Caucasian
  - *Risk:* AA, Asian, Hispanic, Multi-Racial
- Youth Health Insurance
  - *Non-Risk:* Private
  - *Risk:* Public
- Parent Education
  - *Non-Risk:* >/= College
  - *Risk:* < College
- Parent Employment Status
  - *Non-Risk:* Full-Time
  - *Risk:* Not Full-Time
- Parent Occupation
  - *Non-Risk:* Hollingshead (1975) Occupation Code >/= 5
  - *Risk:* Code < 5
- Parent Immigrant Status
  - *Non-Risk:* Non-Immigrant
  - *Risk:* Immigrant
- Parent Language
  - *Non-Risk:* English Speaking
  - *Risk:* Non-English Speaking
- Family Structure
  - *Non-Risk:* Two-Parent Family
  - *Risk:* One-Parent Family
- Family Income-to-Needs Ratio
  - *Non-Risk:* Ratio >/= 1
  - *Risk:* Ratio < 1
- Zip Code Income
  - *Non-Risk:* >/= National Median
  - *Risk:* Below National Median

Health-Related Functioning

- BMI
- Sleep Disturbances
- Lifetime UTIs
- Pain
- Medical Adherence

Neuropsychological Functioning

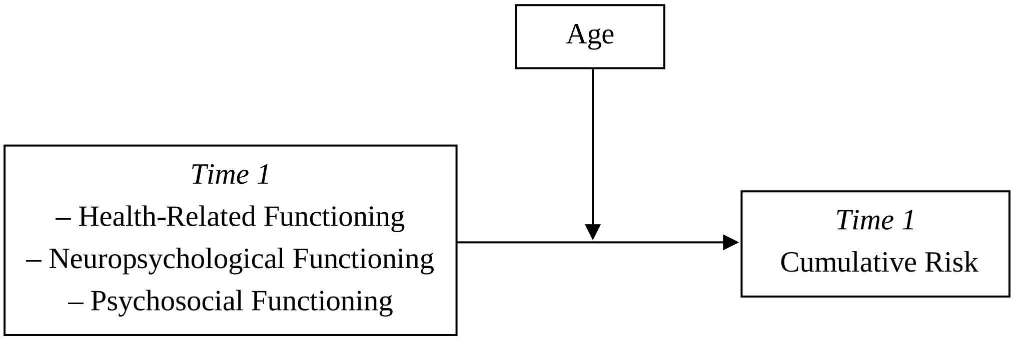
- Attention Problems
- Executive Function Problems
- Academic Achievement

Psychosocial Functioning

- Internalizing Symptoms
- Externalizing Symptoms
- Social Adjustment
- Health-Related Quality of Life

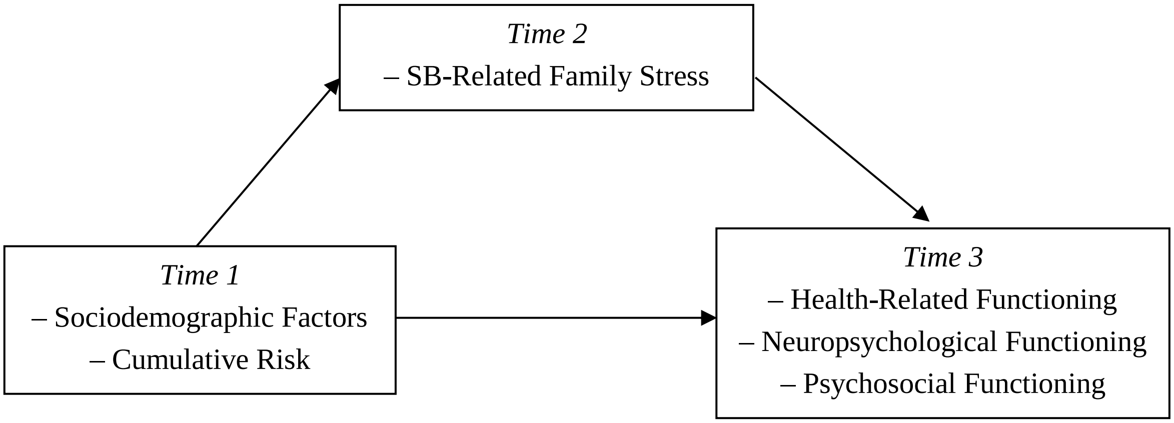
The ***second objective*** was to examine the association between the *cumulative* effect of sociodemographic risk (*cumulative risk*) and youth health-related, neuropsychological, and psychosocial functioning, as moderated by age, all at Time 1. It was hypothesized that greater cumulative risk would be associated with poorer health-related, neuropsychological, and psychosocial functioning concurrently, and these associations will vary based on age, in that they will be stronger for older youth (see Figure 2).

Figure 2. Moderation Model for Objective 2: Associations between Cumulative Risk and Youth Health-Related, Neuropsychological, and Psychosocial Functioning, as Moderated by Age



The ***third objective*** was to examine SB-related family stress as a mediator of the association between cumulative risk and sociodemographic factors, and youth health-related, neuropsychological, and psychosocial functioning over time. It was hypothesized that individual sociodemographic factors characterized by risk and cumulative risk at Time 1 will predict greater SB-related family stress at Time 2, which will, in turn, predict poorer youth health-related, neuropsychological, and psychosocial functioning at Time 3 (see Figure 3).

Figure 3. Mediation Model for Objective 3: Sociodemographic Factors and Cumulative Risk as Predictors of Youth Health-Related, Neuropsychological, and Psychosocial Functioning, as Mediated by Spina Bifida-Related Family Stress



CHAPTER THREE

METHODS

Participants

Participants were part of a larger longitudinal investigation examining family, psychosocial, and neuropsychological functioning among youth with SB (see Devine, Holmbeck, et al., 2012). Families of youth with SB were recruited from four hospitals and a statewide SB association in the Midwest. Families were sent recruitment letters and approached during regularly scheduled clinic visits. Interested families were screened in-person or by phone by a member of the research team. Inclusion criteria for children with SB consisted of: (1) a diagnosis of SB (types included myelomeningocele, lipomeningocele, and myelocystocle); (2) age 8-15 years at Time 1; (3) ability to speak and read English and/or Spanish; (4) involvement of at least one primary caregiver; and (5) residence within 300 miles of laboratory (to allow for home visits for data collection).

A total of 246 families were approached during recruitment, of which 163 agreed to participate. However, of those 163 families, 21 families could not be contacted or later declined, and 2 families did not actually meet inclusion criteria. Thus, the final sample of participants included 140 families of youth with SB (53.6% female; *M* age = 11.43). Of these 140 children, 52.9% were Caucasian, 27.9% were Hispanic, 13.6% were African American, 1.4% were Asian, and 4.3% were multiracial. Hispanic families were oversampled to better study this population of youth with SB. Table 1 displays demographic and SB-related information for youth at Time 1.

Youth of families who declined to participate did not differ from participants with respect to type of SB (myelomeningocele or other) [χ^2 (1) = .0002, $p > .05$], shunt status [χ^2 (1) = .003, $p > .05$], or occurrence of shunt infections [χ^2 (1) = 1.08, $p > .05$].

Table 1. Youth Demographic and Spina Bifida Information at Time 1

	M (SD) or N (%) *n* = 140
Age	11.43 (2.46)
Gender: female	75 (53.6%)
Race/ethnicity	
African American	19 (13.6%)
Asian	2 (1.4%)
Caucasian	74 (52.9%)
Hispanic	39 (27.9%)
Multiracial	6 (4.3%)
Spina bifida type	
Myelomeningocele	122 (87.1%)
Lipomeningocele	10 (7.1%)
Other	8 (5.7 %)
Lesion level	
Thoracic	23 (16.4%)
Lumbar	72 (51.4%)
Sacral	43 (30.7%)
Unknown/not reported	2 (1.4%)
Shunt present	110 (78.6%)
Gross Motor Function	
Level I	18 (12.9%)
Level II	34 (24.3%)
Level III	30 (21.4%)
Level IV	53 (37.9%)
Unknown/not reported	5 (3.5%)
IQ	85.68 (19.67)

Note. Gross Motor Function Level I = minimal limitations and Level IV = high degree of gross motor dysfunction. IQ = WASI estimated full-scale IQ.

Data were collected every two years at three time points. Participants were ages 8-15 at Time 1, ages 10-17 at Time 2, and ages 12-19 at Time 3. Data were collected at Time 2 for 110 (79%) of the original 140 participants. Reasons for attrition at Time 2 (*n* = 30): 17 participants declined to participate, 12 participants were unable to be contacted, and 1 participant was deceased. Data were collected at Time 3 for 103 (74%) of the original 140 participants. Importantly, of the 30 who did not participate at Time 2, 11 participants re-entered the study at Time 3. Reasons for attrition at Time 3 (*n* = 37): 20 participants declined to participate, 16 participants were unable to be contacted, and 1 participant was deceased.

Procedure

The current study was approved by university and hospital Institutional Review Boards and utilized a multi-method, multi-informant longitudinal research design. Data were collected by trained undergraduate and graduate student research assistants during home visits that lasted approximately three hours. At Time 1, two 3-hour home visits were conducted. At subsequent time points, only one 3-hour home visit was conducted due to a shortened protocol. For home visits with families who primarily spoke Spanish in the home, at least one research assistant was bilingual. Informed consent from parents and assent from youth were obtained at the start of the first visit. Parents completed release forms to allow for data collection from medical charts, health professionals, and teachers. Data collected included youth, parent, teacher, health professional, and peer questionnaires; youth, parent, and peer interviews; youth neuropsychological testing; video-recorded family interaction tasks of the child and his/her parent(s); video-recorded peer interaction tasks of the youth and his/her friend; and data collected from review of youth medical charts. The current study includes youth-, parent-, and teacher-reported questionnaire data, youth neuropsychological testing data, and medical chart data. Parents completed identical questionnaires separately. Questionnaires that were only available in English were adapted for Spanish speakers using forward and back translation by a translation team. Families received $150 and small gifts (i.e., logo t-shirts, pens, water bottles) for their participation. Teachers received $25 for completion of the teacher questionnaire, and health professionals received $10 for completion of the health professional questionnaire.

At Time 3, 24 participants were 18 years or older (i.e., “young adults”), and therefore completed an abbreviated study protocol that did include the participation of parents, peers, or teachers. Specifically, the Time 3 young adult protocol included young adult questionnaires, interviews, neuropsychological testing, and medical chart data, all of which is included in the current study with the exception of interview data.

Measures

Unless otherwise noted, all measures were collected at Times 1, 2, and 3. Alphas reported in text are for dependent variables at Times 1 and 3 and for mediating variables at Time 2.

Condition-Related Information

Condition-related variables assessed include SB type, SB lesion level, shunt status, gross motor functioning, and condition severity.

Data regarding youth’s type of SB (i.e., myelomeningocele, lipomeningocele, or other), lesion level (i.e., thoracic, lumbar, or sacral), and shunt status (yes/no) were primarily drawn from medical charts, but in cases where such data were missing, data were drawn from a medical history questionnaire completed by parents.

Gross motor function was coded using the Gross Motor Function Classification System for SB (Wilson, Washington, Engel, Ciol, & Jensen, 2006), designed to capture clinically meaningful distinctions in motor control, with Level I indicating very minimal limitations in gross motor function, to Level V indicating the highest degree of gross motor dysfunction; participants in the present study fell within levels I through IV. Motor classification was coded based on information about motor function and mobility from medical chart data and parent-report on a medical history questionnaire. Coders were trained with actual study cases and all coders achieved pre-determined standards for inter-rater reliability (≥ 90% agreement rate) during training. Following training, a single coder provided motor classifications for each participant. The original GMFCS scale has demonstrated good inter-rater agreement (Kappa = .75 for children 2 years and older; Palisano et al., 1997).

A condition severity composite score was computed for each participant, with scores ranging from 4 to 11 (higher scores indicate higher levels of severity). Scores were computed based on the following variables: myelomeningocele (no = 1, yes = 2), lesion level (sacral = 1, lumbar = 2, thoracic = 3), shunt status (no = 1, yes = 2), and gross motor function classification (Level I = 1, Level 2 = 2, Level 3 = 3, Level 4 = 4). Six participants did not have complete date for all 4 variables used to create the condition severity composite. Therefore, each participant's sum score was divided by the highest possible sum based on their available data, to generate a condition severity percentage.

Sociodemographic Information

Parents reported on youth and family sociodemographic information through questionnaires. Parents reported on child age, gender, race/ethnicity, and health insurance.

Parents also reported on their age, gender, race/ethnicity, education, occupation, employment status, immigrant status, preferred language, family structure, family income, and number of family members living in the home.

Data from mother-report was given preference for all variables. If mother-reported data was missing, father-reported data was used. For single-parent families, data from one parent was used in all cases. For two-parent families, consideration was given to both mother- and father-reported data when necessary. For example, for two-parent families, only mother-report of child race/ethnicity was used unless mother-report data is missing, whereas both mother- and father-report of parent education was considered.

Detailed information on select sociodemographic variables is provided below, including use of parent-reports from single- versus two-parent families, and information on how variables were dichotomized into categories of non-risk and risk.

Youth race/ethnicity. Parents reported their child's race/ethnicity as being White, African American, Hispanic, Asian, other (*non-risk* = Caucasian; *risk* = African American, Asian, Hispanic, multi-racial).

Youth health insurance. Parents completed an open-ended item asking "What type of health insurance does your child have," (*non-risk* = private health insurance; *risk* = public health insurance).

Parent education. Parents reported their level of education as being in one of the following categories: some grade school, finished grade school, some high school, high school graduate or GED, business or technical school, some college, finished college, some graduate or professional school after college, professional degree (*non-risk* = college education for at least one parent; *risk* = less than college education for both parents or single parent).

Parent employment status. Parents reported their employment status as being full-time homemaker, retired, on disability from work, employed part-time, or employed full-time (*non-risk* = employed full-time for at least one parent; *risk* = no full-time employment for at least one parent or single parent).

Parent occupation. Parents reported their occupation. Responses were coded according to the Hollingshead occupation codes (Hollingshead, 1975). These codes represent the following nine categories: 1 = Farm Laborers/Menial Service Workers; 2 = Unskilled Workers; 3 = Machine Operators and Semiskilled Workers; 4 = Smaller Business Owners, Skilled Manual Workers, Craftsmen, and Tenant Farmers; 5 = Clerical and Sales Workers, Small Farm and Business Owners; 6 = Technicians, Semiprofessionals, Smaller Business Owners; 7 = Smaller Business Owners, Farm Owners, Managers, Minor Professionals; 8 = Administrators, Lesser Professionals, Proprietors of Medium-Sized Businesses; 9 = Higher Executives, Proprietors of Large Businesses, and Major Professionals (*non-risk* = Hollingshead (1975) occupation code of 5 or more for at least one parent; *risk* = Hollingshead (1975) occupation code of less than 5 for both parents or single parent).

Parent immigrant status. Parents reported on their country of birth (*non-risk* = born in the United States for both parents or single parent; *risk* = at least one parent born outside of the United States.)

Parent language. Parents reported their preferred language (*non-risk* = English is the preferred language for both parents or single parent; *risk* = English is not the preferred language for at least one parent).

Family structure. Parents reported their marital status as being married, separated, divorced, widowed, cohabitating, or single (*non-risk* = two-parent family as indicated by parent status of married or cohabitating; *risk* = single-parent family as indicated by parent status of separated, divorced, widowed, or single).

Family income. Parents reported the family's annual income as one of 21 categories indicating income in amounts of $10,000, beginning at "under $10,000" and going up to "over $200,000."

Income-to-needs ratio. The family's income-to-needs ratio was calculated by dividing parent-reported annual family income by the 2009 standard of 150% of the federal poverty line (USDHHS, 2009) for a family of the same size (*non-risk* = ratio equal or greater to 1; *risk* = ratio less than 1).

Zip code income. Participants' residential zip codes from Time 1 and data from the American Community Survey (ACS; USCB, 2010) was used to determine the median annual household income for participants' residential area. The ACS provides public data on the median household income for every national zip code as reported from 2006-2010 (*non-risk* = zip code income at or above the national median household zip code income; *risk* = zip code income below the national median; Franks, Tancredi, Winter, & Fiscella, 2010).

Cumulative risk. A cumulative risk index was calculated for each participant using ten sociodemographic factors that were dichotomized and assigned a value of 0 (risk absent) or 1 (risk present). The values were summed to calculate the cumulative risk index, with scores ranging from 0 to 10. This approach is consistent with past research on cumulative risk (Rutter, 1993). Sociodemographic factors included youth race/ethnicity, youth health insurance, parent education, parent employment status, parent occupation, parent immigrant status, parent language, family structure, income-to-needs ratio, and zip code income.

Health-Related Functioning

Health-related functioning was assessed by examining health-related variables that are hypothesized to be impacted by sociodemographic factors based on past research. These variables include: BMI, sleep disturbances, number of lifetime UTIs, pain, and medical adherence.

Body mass index (BMI). Parents reported on youth height and weight on a health questionnaire adapted for this study from the CDC's 1999 Youth Risk Behavior Survey (CDC, 1999). In cases where parent report was unavailable, data from medical charts were used. BMI percentile scores for each participant were computed by entering age, gender, height, and weight into the CDC's *BMI Percentile Calculator for Children and Teenagers* (i.e., weight divided by height squared, plotted on standardized gender-specific CDC growth charts; CDC, 2015).

Sleep disturbances. Sleep disturbances were measured using parent responses to six items of the Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2001). Items assessed the degree to which the youth has nightmares, sleeps less than most children, sleeps more than most children, talks or walks in their sleep, has trouble sleeping, and is overtired. Parents rated each item on a 3-point scale (0 = "not true," 1 = "somewhat true," and 2 = "very true"). The mean of all 6 items were used in the present study, with higher scores indicating greater sleep disturbances. The CBCL sleep composite score has been recommended as a measure of sleep functioning (Becker, Ramsey, & Byars, 2015), and has demonstrated convergent validity with other measures of sleep functioning in children and adolescents aged 6–18 years (e.g., youth report on the Adolescent Sleep-Wake Scale; Becker er al., 2015; α's = .59 and .55 for mother- and father-report, respectively, at Time 1; α's = .56 and .49 for mother- and father-report, respectively, at Time 3).

Urinary tract infections (UTIs). Parents reported on the number of lifetime UTIs on a medical history questionnaire. In cases where such data were missing, data were drawn from the medical chart.

Pain. Youth completed the Pain Questionnaire, (Klepper, 1999; Palermo, Zebracki, Newman, & Singer, 2004), which includes 14 items to assess a variety of pain characteristics (e.g., intensity, frequency, duration, emotional upset, location). The current study included two items assessing pain frequency and pain intensity. Participants were asked to rate the frequency of their pain over the past 3 months by selecting one of five categories ("less than once per month" to "daily"); responses were transformed to indicate number of days per month pain was experienced. Participants were asked to rate the intensity of their pain on a visual analogue scale, by marking the point along a 10-centimeter line (0 = "no pain" and 10 = "worse pain ever"). An overall pain score was computed by multiplying pain frequency by intensity, with higher scores indicating greater pain.

Medical Adherence. Youth adherence to their SB medical regimen was measured by parent-report on the Spina Bifida Self-Management Profile (SBSMP; Wysocki & Gavin, 2006), a 14-item structured interview that was adapted to questionnaire format for the current study. Items assess the degree to which youth are adherent to a range of SB-related tasks, including bowel program, catheterization, UTI management, skin and wound care, medications, exercise, and appointment keeping. Each item is rated on a likert scale, and items that were not applicable could be indicated as such. An example is, “In the past 6 months, how often did you and your child check your child’s skin?” (1= “rarely check skin” and 5 = “checks all over the body every day”). The current study used the mean of all endorsed items, with higher scores indicated greater adherence. Owing to the number of participants who completed each item (i.e., parents could endorse “not applicable” for certain items), scale reliability could not be computed.

Neuropsychological Functioning

Neuropsychological functioning was assessed by examining attention problems, executive function problems, and academic achievement. IQ was included in analyses as a covariate. Both performance-based (i.e., WASI, WRAT) and questionnaire (i.e., BRIEF, CBCL/TRF, SNAP) measures were used to provide a broad-based measure of neuropsychological functioning.

IQ. General intellectual ability was measured using the Vocabulary and Matrix Reasoning subtests of the Wechsler Abbreviated Scale of Intelligence (WASI; Wechsler, 1999) to compute an estimated full-scale IQ (FSIQ). The WASI is a well-validated measure of child intelligence with normative means of 100 and standard deviations of 15. The Vocabulary subtest is a 42-item task used to measure child’s expressive vocabulary, verbal knowledge, and fund of knowledge. The Matrix Reasoning subtest is a 35-item task used to measure nonverbal fluid reasoning and general intellectual ability. These subtests have demonstrated high levels of internal consistency for all ages 6-89 years (Wechsler, 1999).

Attention problems. Attention problems were measured using parent- and teacher-report on the Swanson, Nolan, and Pelham Rating Scale-IV (SNAP-IV; Swanson et al., 2001), a measure based on the DSM-IV (APA, 1994) criteria for Attention-Deficit/Hyperactivity Disorder (ADHD). The current study used the 9 inattention items (e.g., “Often does not seem to listen when spoke to directly”) which were rated on a 4-point scale (1 = “not at all” and 4 = “very much”). The current study used the mean of all 9 items, with higher scores indicating greater attention problems (α’s = .93, .92, and .94 for mother-, father-, and teacher-report, respectively, at Time 1; α’s = .95, .92, and .56 for mother-, father-, and teacher-report, respectively, at Time 3).

Attention problems were also measured using parent-report on the Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2001) and teacher-report on the Teacher Report Form (TRF; Achenbach & Rescorla, 2001). The CBCL and TRF consist of 118 items that describe behavioral and emotional problems, each rated on a three-point scale (0 = “not true”, 1 = “somewhat or sometimes true”, 2 = “very true or often true”). This study will use T scores from the Attention Problems subscale, with higher scores indicating greater attention problems.

Executive function problems. Executive functions problems were measured using parent- and teacher-report on the Behavior Rating Inventory of Executive Functions (BRIEF; Gioia, Isquith, Guy, Kentworthy, 2000), which is a measure of everyday executive functions in home and school environments. The BRIEF consists of eight sub-domains that fall within two broad second-order scales: Behavioral Regulation which contains the Inhibit, Shift, and Emotional Control sub-domains, and Metacognition which contains the Initiate, Working Memory, Plan/Organize, Organization of Materials, and Monitor sub-domains. The parent-report version includes 85 items whereas the teacher-report version includes 86 items. Example items include "Makes careless mistakes" or "Forgets what he/she is doing in the middle of things" and are rated on a 3-point scale, as "never," "sometimes," or "often" a problem. Mean scores were used in the current study, with higher scores indicating more executive function problems (α's = .97, .97, and .89 for mother-, father-, and teacher-report, respectively, at Time 1; α's = .98, .98, and .98 for mother-, father-, and teacher-report, respectively, at Time 3).

Academic achievement. Youth were administrated the reading, spelling, and arithmetic subtests of the Wide Range Achievement Test-3 (WRAT-3; Wilkinson, 1993) to assess basic academic ability at Times 1 and 3 only. The reading subtest assesses an individual's ability to recognize and name 15 letters and pronounce 42 words out of context. The spelling subtest includes writing one's own first and last name, 13 dictated letters, and 40 dictated words. The arithmetic subtest includes 55 items across oral and written sections that are comprised of counting, recognition of letter and number symbols, and computation. Raw scores were converted to standard scores. The WRAT-3 is age-normed for individuals 5 to 75 years and has demonstrated adequate internal consistency across subscales (α's = .85 to .90; Wilkinson, 1993).

Psychosocial Functioning

Youth psychosocial functioning was assessed by examining internalizing symptoms, externalizing symptoms, social adjustment, and health-related quality of life.

Internalizing and externalizing symptoms. Youth completed the Children's Depression Inventory (CDI; Kovacs, 1992), a measure of depressive symptoms in children. It includes 27 items that consist of three choices that are rated as 0, 1, or 2, with higher scores indicating greater severity. The mean of all 27 items was used in the current study (α's = .80 and .77 at Times 1 and 3, respectively).

Parents completed CBCL and teachers completed the TRF (see previous description of the CBCL and TRF; Achenbach & Rescorla, 2001). The CBCL and TRF yield T-scores on Internalizing Problems and Externalizing Problems subscales, which were used for this study.

Social adjustment. According to Cavell (1990), social adjustment is the degree to which an individual is achieving developmentally appropriate goals, and may be measured by *perceived social competence, peer acceptance,* and *quality of friendships* (Devine, Holmbeck, et al., 2012); thus, these three social adjustment constructs were examined in the current study.

Perceived social competence. Youth completed the Children's Self Efficacy for Peer Interaction Scale (CSPI; Wheeler & Ladd, 1982), which assesses youth's perceived self-efficacy in social situations. The scale consists of 22 items describing a social situation (e.g., "Some kids want to play a game") and is followed by an incomplete statement requiring the respondent to evaluate his/her ability to perform a verbal persuasive skill (e.g. "Asking them if you can play is __________ for you"). The respondent answers each item using a 4-point scale (1 = "very hard" and 4 = "very easy") with higher scores indicating greater self-efficacy. For this study, four items were dropped because the wording was not age appropriate (e.g., "using your play area"). The current study will use the mean across all 18 items (α's = .82 and .91 at Times 1 and 3, respectively).

Parents completed the social competence subscale from the CBCL (see previous description of CBCL; Achenbach & Rescorla, 1991), which contains 9 items regarding: a) participation in organizations, clubs, teams, or groups, b) number of close friends, c) amount of time spent with friends outside of regular school hours, and d) behavior with others (i.e., how well the child gets along with their brothers and sisters, other kids, their parents) and behavior when alone (i.e., how well the child does things by themselves). The CBCL yields T-scores on the Social Competence subscale, which were used for this study.

Peer acceptance. Youth, parents, and teachers completed the Social Acceptance subscale from the appropriate reporter versions of Harter's (1985) Self-Perception Profile for Children Scale (SPPC) to assess youth acceptance by peers; youth completed the What I Am Like, (WIAL-C), parents completed the Parent's Rating Scale of Child's Actual Behavior (PRSCAB), and teachers completed the Teacher's Rating Scale of Child's Actual Behavior (TRSCAB). All three versions consist of items for which the respondent is asked to identify which of two statements best describes the youth (e.g., "My child finds it hard to make friends" or "For my child it's pretty easy"), and then to decide whether the statement is "really true" or "sort of true." The child version subscale consists of 6 items and the parent and teacher version subscales consist of 3 items, with higher scores (ranging from 1 to 4) indicating greater peer acceptance. The current study used mean scores (α's = .67, .67, .76, and .60 for mother-, father-, teacher-, and child-report, respectively, at Time 1; α's = .72, .59, .72, and .82 for mother-, father-, teacher-, and child-report, respectively, at Time 3).

Friendship quality. Youth completed the Friendship Activity Questionnaire (FAQ) based on the Friendship Qualities Scale (FQS; Bukowski, Hoza, & Boivin, 1994). The FAQ consists of 46 items across five scales of friendship qualities: companionship (e.g., "My friend and I spend a lot of our free time together"), conflict (e.g., "I can get into fights with my friend"), help (e.g., "If other kids were bothering me, my friend would help me"), security (e.g., "If I have a problem at school or at home, I can talk to my friend about it"), and closeness (e.g., "I think about my friend even when my friend is not around"). Respondents are asked to rate how true each statement is for his/her closest friendship on a five-point scale (1 = "not true" and 5 = "really true") with higher scores indicating better friendship quality. The current study used the mean score (α's = .90 and .91 at Times 1 and 3, respectively).

Youth also completed the Emotional Support Questionnaire Scale (ESQ; Slavin, 1991) to assess peer social support. This measure asks youth to nominate three individuals from each of the three categories: family members, non-family adults, and peers. Respondents rate each relationship on 4 items: how much they talk about personal concerns, how close they feel to the individual, how much the individual rated talks to the respondent, and how satisfied they are with the support they receive. The following 3 items were added for this study: how much do the respondent and the other individual get upset with or mad at each other, how much does the respondent play around and have fun with the other individual, and how sure the respondent is that this relationship will last no matter what. Respondents are asked to rate each item on a four-point scale (1 = "hardly at all" and 4 = "very true"). The current study utilized data on how respondents rate their peer relationships by computing a mean score across all 7 items (α's = .88 and .85 at Times 1 and 3, respectively).

Health-related quality of life. Youths' HRQOL was assessed using parent- and youth-report on the PedsQL Scale (PedsQL 4.0 Generic Core Scales; Varni, Seid, & Kurtin, 2001). The PedsQL has well-established reliability and validity in children with both acute and chronic health conditions, and yields an 8-item physical scale as well as a 15-item psychosocial scale; the current study used only the psychosocial scale. The psychosocial scale is composed of three subscales: emotional (five items), social (five items), and school functioning (five items). Youth and parents answered how much of a problem a given task had been over the past month using a 5-point scale (0 = “never a problem” to 4 = “almost always a problem”). The following are sample questions from the psychosocial scale of the youth version: “I feel sad or blue” (emotional); “Other kids do not want to be my friend” (social); “I have trouble keeping up with my schoolwork” (school). The current study used mean scores, with higher scores indicating greater HRQOL (α’s = .79, .86, and .81 for mother-, father-, and child-report, respectively, at Time 1; α’s = .76, .84, and .81 for mother-, father-, and child-report, respectively, at Time 3).

Spina Bifida-Related Family Stress

Parents completed the Family Stress Scale (FSS; Quittner, Glueckauf, & Jackson, 1990), which consists of 19 items to assess common stressors in families of a child with SB. Thirteen items are non-disease specific (e.g., “mealtimes and bedtimes”) and 6 items are disease-specific (e.g., “medical care/appointments”). Items are rated using a 5-point scale (1 = “not at all stressful” and 5 = “extremely stressful”), with higher scores indicating higher levels of stress. The current study used the mean of all 19 items (α’s = .92 and .90 for mother- and father-report, respectively, at Time 2).

Young Adult Measures

As mentioned previously, participants who were 18 years or older at Time 3 completed the young adult protocol, which excluded the participation of parents and teachers. The Time 3 young adult protocol included many of the same youth-reported measures as well as self-report versions of most parent-reported measures. However, some of the measures were modified or not included for those who completed the young adult protocol at Time 3 (see the following paragraph). Thus, young adult participants were still included in the present study, and analyses included the data that were available, but some missing data is owed to measures that were not included for participants who were young adults at Time 3.

Specifically, for ***sociodemographic factors***, *family structure* and *family income* data were not collected, thus, *income-to-needs ratio* was not calculated. For ***health-related outcomes***, *BMI* was not calculated because height and weight data were not collected, *pain* and *adherence* were not assessed, and *sleep disturbances* was measured through the Adult Self-Report for ages 18–59 (ASR; Achenbach & Rescorla, 2003). For ***neuropsychological outcomes***, attention problems were measured using the ASR (Achenbach & Rescorla, 2003); the SNAP-IV (Swanson et al., 2001) was not completed. For ***psychosocial outcomes***, internalizing and externalizing symptoms were measured through the ASR (Achenbach & Rescorla, 2003); the CDI (Kovacs, 1992) was not completed. For social adjustment, *perceived social competence* was not assessed, and the ESQ (ESQ; Slavin, 1991) was not completed as a measure of *friendship quality*. Lastly, ***SB-related family stress*** was not assessed.

Statistical Treatment

All analyses were conducted using Statistical Package for the Social Sciences (SPSS) Version 24.0.

Preliminary Analyses

Prior to hypothesis testing, the psychometric properties of all measures were evaluated, including examining the distributional properties of all outcome variables (i.e., testing for skewness and outliers). Data transformation techniques were used when appropriate.

The present study had missing data due to item non-response, attrition, and an altered study protocol for youth 18 years and older at Time 3 (i.e., no involvement of parents and teachers). For all variables across all three time points, a non-significant Little's missing completely at random (MCAR) test (Little, 1988) revealed that data were missing completely at random, 20.30% missing, $\chi^2(2790) = 2889.60$, $p = .09$. Listwise deletion was used to handle missing data, as this is considered a valid approach when data are found to be MCAR (Schafer & Graham, 2002).

To reduce the number of potential analyses, data reduction techniques were used. Specifically, either Pearson correlation coefficients (for two reporters) or Cronbach's alpha coefficients (for three or more reporters, or for multiple measures, with scales treated as individual items in a reliability analysis) were computed to assess, first, associations among multiple reporters (i.e., youth, mother, father, teacher), and then associations among data from multiple measures for each construct (e.g., the CDI and CBCL for internalizing symptoms). If data were significantly correlated ($r > .40$, $p < .05$) or had adequate internal consistency ($\alpha > .60$), composite scores were created.

Descriptive statistics, bivariate correlations, and *t*-tests were conducted to determine the associations among all study variables.

Hypothesis Testing

Covariates. The covariates that were included in analyses varied for each objective. First, given that the range in participant age at each time point spans developmental stages (ages 8-15 at Time 1, ages 10-17 at Time 2, and ages 12-19 at Time 3), **age** was included as a covariate in analyses for Objectives 1 and 3 to understand whether associations among study variables exist regardless of age (development stage; see Tables 3 and 4 for correlations between age and study variables). Objective 2 aims to understand whether the associations among variables varied based on age, which is why it was included as moderator and not a covariate. Second, descriptive statistics revealed a significant difference in IQ between risk and non-risk groups across most sociodemographic variables. Given this, and to be consistent with past literature (e.g., Papadakis et al., 2018), **IQ** was included as a covariate in all analyses. Third, there was a range in condition severity in this study's sample (see Table 1), consistent with the larger SB population (Copp et al., 2015). To understand whether associations among study variables regardless of the severity of one's condition, **condition severity** was included as a covariate in all analyses (see Tables 3 and 4 for correlations between condition severity and study variables).

Analytic plan for objective 1. The first objective was to examine differences in health-related, neuropsychological, and psychosocial functioning between youth who *are* and *are not* characterized by *risk* for each sociodemographic factor at Time 1 (see Figure 1). This objective was examined by conducting multivariate analyses of covariance (MANCOVAs) with univariate follow-up analyses. Three MANCOVAs (one each for health-related, neuropsychological, and psychosocial functioning outcomes) were tested for each sociodemographic factor. Analyses included youth age, IQ, and condition severity as covariates. Assuming a power of .80 and an alpha of .05, a sample of 26 is required to detect large effect sizes ($\eta^2 = .40$) and a sample size of 64 is required to detect medium effect sizes ($\eta^2 = .25$) for analyses with 2 groups (Cohen, 1992). Thus, the current study had enough power to detect medium to large effect sizes.

Analytic plan for objective 2. The second objective was to examine the association between the *cumulative* effect of sociodemographic *risk* (i.e., *cumulative* risk) at Time 1 and youth health-related, neuropsychological, and psychosocial functioning at Time 1, as moderated by age at Time 1 (see Figure 2). This objective was examined by conducting hierarchical multiple regression analyses testing moderation effects based on methods outlined by Aiken and West (1991) and Holmbeck (1997, 2002). A separate regression analysis was conducted for each outcome. Variables were entered simultaneously within the following steps: (1) covariates, (2) cumulative risk index main effect and age main effect, (3) cumulative risk index X age interaction. Covariates included youth IQ and condition severity. Assuming a power of .80 and an alpha of .05, a sample of 38 is required to detect large effect sizes ($R^2 = .35$) and a sample size of 84 is required to detect medium effect sizes ($R^2 = .15$) for analyses with 4 predictors (Cohen, 1992). Thus, the current study had enough power to detect medium to large effect sizes.

Analytic plan for objective 3. The third objective was to examine SB-related family stress at Time 2 as a mediator of the longitudinal association between cumulative risk and sociodemographic factors at Time 1, and youth health-related, neuropsychological, and psychosocial functioning at Time 3 (see Figure 3). This objective was examined by using bootstrapping methods, which have been validated in the literature and is preferred over other methods, such as the Sobel Test (Hayes, 2009; Hayes, 2013; MacKinnon, Warsi, & Dwyer, 1995; Preacher & Hayes, 2008). The Sobel Test (Sobel, 1982) uses a normal approximation which presumes a symmetric distribution. Because it falsely presumes symmetry, it is a more conservative test, yielding very low power. With bootstrapping, there are fewer parameter estimates and power is higher, which reduces the possibility of Type II errors. This procedure generates an empirical approximation of the product of the estimated coefficients' sampling distribution in the direct path, percentile-based bootstrap confidence intervals (CI), and bootstrap measures of standard errors using 5,000 resamples, with replacement, from the dataset. When zero is not between the upper and lower bounds of the confidence interval, it can be claimed with 95% confidence that the indirect effect is not zero, indicating a significant indirect effect (Hayes, 2009; Hayes, 2013; MacKinnon et al., 1995; Preacher & Hayes, 2008). The current study used Hayes' PROCESS v2.16 statistical software to conduct bootstrapping analyses. Analyses controlled for youth age, IQ, condition severity, and the dependent variable at Time 1. When using percentile bootstrapping methods and assuming a power of .80, and an alpha of .05, a sample size of 36 is required to detect large effect sizes and a sample size of 78 is required to detect medium effect sizes (Fritz & MacKinnion, 2007). Thus, the current study had enough power to detect medium to large effect sizes.

CHAPTER FOUR

RESULTS

Preliminary Analyses

All variables were examined for outliers and all dependent variables were tested for skewness. Following the conservative approach recommended by Tabachnick & Fidell (2013), variables were considered skewed and were transformed if skewness values were greater than 1.0. In addition, if a variable was skewed at one time point, it was transformed at all three time points. Results indicated that two variables were positively skewed: UTIs and pain. Both variables were first transformed using square root transformation, but they remained skewed; therefore, log transformation was used. At Times 1, 2, and 3, respectively, UTIs had skewness values of 5.61, 2.46, and 7.03; these values reduced to 1.81, 0.65, and 3.96 after square root transformation and 0.66, 0.27, and 0.31 after log transformation. Pain had skewness values of 2.89, 3.48, and 5.81; these values reduced to 1.89, 2.14, and 2.38 after square root transformation, and 0.13, 0.02, and 0.13 after log transformation.

Data reduction techniques were used to reduce the number of analyses by examining the associations among multiple reporters and multiple measures of each construct. Specifically, Pearson correlation coefficients (for two reporters) or Cronbach’s alpha coefficients (for three or more reporters, or for multiple measures, with scales treated as individual items in a reliability analysis) were conducted and, if data were significantly correlated ($r > .4$, $p < .05$) or had adequate internal consistency ($\alpha > .6$), composite scores were computed. For some variables, composites were created by collapsing across *both* reporters *and* measures. For constructs that included different measures (e.g., attention was measured using the CBCL and SNAP-IV), scores were first transformed into *z* scores. Results indicated that the following variables were significantly correlated or demonstrated adequate internal consistency, so were averaged together at each time point; statistics are listed for Times 1 and 3, respectively, for each construct except SB-related family stress, for which statistics represent Time 2: mother- and father-report of sleep disturbances on the CBCL (r = .63, p < .001, α = .74 across all mother and father items; r = .56, p < .001, α = .65 across all mother and father items); mother- and father-report of medical adherence on the SBSMP (r = .57, p < .001, r = .58, p < .001); mother-, father-, and teacher-reports of attention on the CBCL and SNAP-IV (α's = .68 and .77); mother-, father-, and teacher-reports of executive function on the BRIEF (α's = .65 and .81); the reading, writing, and math subscales of the WRAT (α's = .93 and .90); mother-, father-, and teacher-reports of internalizing symptoms on the CBCL and youth-report on the CDI (α's = .54 and .53); mother-, father-, and teacher-reports of externalizing symptoms on the CBCL (α's = .60 and .65); mother- and father-report on the CBCL and youth-report on the CSPI for social competence, mother-, father-, teacher-, and youth-report on the HARTER for peer acceptance, and youth-report on the FAQ and ESQ for friendship quality (α's = .77 and .78); mother-, father-, and youth-reports of HRQOL on the PedsQL (α's = .60 and .68); mother- and father-report of SB-related family stress on the FSS (r = .45, p < .001).

T-tests were conducted to determine differences in covariates (age, IQ, condition severity) between risk and non-risk groups for each of the 10 sociodemographic variables at Time 1. There were no significant differences in age between risk and non-risk groups for any of the 10 sociodemographic variables (*p*'s > .05). There was a significant difference in IQ between risk and non-risk groups across all sociodemographic variables except family structure, in that risk groups had significantly lower IQ scores (*p*'s < .05). Lastly, there was a significant difference in condition severity between risk and non-risk groups for parent education and occupation, in that risk groups had significantly greater condition severity (*p*'s > .05). *T*-tests were also conducted to determine differences in SB-related family stress at Time 2 for each sociodemographic variable at Time 1. There was a significant difference in SB-related family stress between risk and non-risk groups for race/ethnicity, insurance, parent education, and parent occupation, in that, contrary to expectations, risk groups had significantly *lower* SB-related family stress (*p*'s > .05).

Table 2 displays descriptive information on the cumulative risk index at Time 1.

Table 2. Descriptive Information on Cumulative Risk Index

	M (SD) or N (%) *n* = 97
Cumulative Risk Index	3.26 (2.56)
0 Risks	14 (14.4%)
1 Risk	18 (18.6%)
2 Risks	16 (16.5%)
3 Risks	7 (7.2%)
4 Risks	10 (10.3%)
5 Risks	10 (10.3%)
6 Risks	5 (5.2%)
7 Risks	12 (12.4%)
8 Risks	4 (4.1%)
9 Risks	1 (1.0%)
10 Risks	0 (0.0%)

Note. Sample was reduced from full sample of *n* = 140 because Cases with missing data on any single sociodemographic factor used to create cumulative risk index were not included.

Table 3 displays bivariate correlations among cumulative risk, outcome variables, and covariates (age, IQ, condition severity), all at Time 1. The only significant correlation that was in the unexpected direction was between cumulative risk and UTIs ($r = -.23$, $p < .05$). Table 4 displays bivariate correlations among cumulative risk and covariates (age, IQ, condition severity) at Time 1 (duplicated from Table 3), but with SB-related family stress at Time 2 and outcome variables at Time 3. Significant correlations that were in unexpected directions include those between cumulative risk and attention problems ($r = -.24$, $p < .05$), cumulative risk and executive function problems ($r = -.20$, $p < .05$), and cumulative risk and SB-related family stress ($r = -.30$, $p < .001$).

Table 3. Correlations among Cumulative Risk, Health-Related, Neuropsychological, and Psychosocial Functioning, and Covariates, all at Time 1

Variable	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.	15.	16.
1. CR	–	.21	.10	-.30**	.39**	.15	-.16	-.17	-.34**	.18	-.03	-.25*	-.05	.14	-.43***	.17
Health																
2. BMI		–	.15	.06	.01	.01	-.18	-.17	-.06	.08	-.06	-.18	.06	.22*	-.20*	.21*
3. Sleep			–	.121	.09	.02	.13	.13	-.11	.36***	.32***	-.06	-.28**	.01	-.08	.07
4. UTI[a]				–	-.24	.07	-.18	-.20	.20	-.10	-.01	.21*	.13	-.05	.27**	.22*
5. Pain[a]					–	.22	.06	.05	-.28*	.32**	.18	-.09	-.26*	-.04	-.30**	.15
6. Adherence						–	-.24**	-.29**	-.03	-.14	-.23*	.05	.00	.06	-.13	.33***
Neuropsych																
7. Att Problems							–	.87***	-.23**	.46***	.48***	-.52***	-.36***	-.07	-.30**	.08
8. EF Problems								–	-.19*	.44***	.59***	-.47***	-.36***	-.13	-.24**	.07
9. Academics									–	-.23*	-.10	.37***	.18	-.18*	.75***	-.13
Psychosocial																
10. Int Sx										–	.54***	-.47***	-.48***	.05	-.30**	.03
11. Ext Sx											–	-.21*	-.25**	-.15	-.11	-.13
12. Social												–	.41***	-.16	.45***	-.16
13. HRQOL													–	.03	.23**	-.12
Covariates																
14. Age														–	-.24**	.13
15. IQ															–	-.31***
16. Severity																–

Note. *n's* range from 81 to 140 across variables. CR = cumulative risk. BMI = body mass index percentile. Sleep = sleep disturbances. UTI = lifetime number of urinary tract infections. Neuropsych = Neuropsychological. Att Problems = attention problems. EF Problems = executive function problems. Int Sx = internalizing symptoms. Ext Sx = externalizing symptoms. Social = (positive) social adjustment. HRQOL = health-related quality of life. IQ = WASI estimated full-scale IQ. Severity = condition severity. [a]This variable was log transformed to correct for skewness. *$p < .05$, ** $p < .01$, ***$p < .001$.

Table 4. Correlations among Cumulative Risk and Covariates at Time 1, SB-Related Family Stress at Time 2, and Health-Related, Neuropsychological, and Psychosocial Functioning at Time 3

Variable	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.	15.	16.	17.
1. CR	–	.29*	.02	-.34*	.27	.18	-.31*	-.23*	-.43***	.02	-.13	-.08	-.13	-.35**	.14	-.43***	.17
Health																	
2. BMI		–	.20	.13	.36*	.47**	.09	-.02	-.27	.32*	.05	-.21	-.17	-.13	.28	-.19	-.27*
3. Sleep			–	.19	-.17	-.23	.16	.13	-.08	.37**	.14	-.30*	-.33*	.49***	.07	.16	.01
4. UTI^a				–	-.22	-.06	.34*	.23	.20	.18	.06	-.29	.06	.29	.06	.36*	.03
5. Pain^a					–	.36*	.10	.13	-.46*	.38*	-.06	-.35*	-.42*	-.14	.01	-.30	.19
6. Adherence						–	-.14	-.17	-.14	.09	-.15	-.08	.09	-.21	.22	-.16	.26
Neuropsych																	
7. Att Problems							–	.85***	-.24	.27*	.49***	-.45***	-.43**	.40**	-.04	-.05	-.01
8. EF Problems								–	-.22	.42***	.65***	-.48***	-.44***	.42***	-.07	.05	-.12
9. Academics									–	-.07	.00	.46**	.07	-.02	-.20	.79***	-.27**
Psychosocial																	
10. Int Sx										–	.61***	-.53***	-.52***	.33**	.08	.05	-.01
11. Ext Sx											–	-.32*	-.30*	.26*	-.16	.18	-.42***
12. Social												–	.53***	-.32*	.07	.31*	-.11
13. HRQOL													–	-.41**	.12	.04	-.17
Mediator																	
14. Stress														–	-.20	.18	.07
Covariates																	
15. Age															–	-.24**	.13
16. IQ																–	-.31***
17. Severity																	–

Note. *n's* range from 47 to 140 across variables. Correlations among cumulative risk and covariates at Time 1 are replications of that presented in Table 2. CR = cumulative risk. BMI = body mass index percentile. Sleep = sleep disturbances. UTI = lifetime number of urinary tract infections. Neuropsych = neuropsychology. Att Problems = attention problems. EF Problems = executive function problems. Int Sx = internalizing symptoms. Ext Sx = externalizing symptoms. Social = (positive) social adjustment. HRQOL = health-related quality of life. Stress = SB-related family stress. IQ = WASI estimated full-scale IQ. Severity = condition severity. ^{a}This variable was log transformed to correct for skewness. *$p < .05$, ** $p < .01$, ***$p < .001$.

Hypothesis Testing

Objective 1

The first objective was to examine differences in health-related, neuropsychological, and psychosocial functioning between youth who *are* and *are not* characterized by *risk* for each sociodemographic factor at Time 1. Analyses controlled for age, IQ, and condition severity. It was hypothesized that, compared to youth *not* characterized by sociodemographic risk, those who *are* characterized by sociodemographic risk would demonstrate poorer health-related, neuropsychological, and psychosocial functioning.

Refer to Table 5 for results related to health-related functioning. Adjusted means (due to log transformation of variables) are presented in the table and represent data that is included in analysis after inclusion of covariates. In text, non-adjusted means represent the mean of all available data. There was a significant difference in health-related functioning based on family income-to-needs. Contrary to hypotheses, follow-up univariate analyses revealed a significant difference in number of lifetime UTIs, in that youth who had a low family income-to-needs ratio had significantly *less* UTIs (M = 0.69; non-adjusted M = 6.15) compared to youth who had a higher ratio (M = 0.45; non-adjusted M = 3.65). Consistent with hypotheses, univariate analyses also revealed a significant difference in pain, in that youth who had a low family income-to-needs ratio had significantly more pain (M = 1.30; non-adjusted M = 51.47) compared to youth who had a higher ratio (M = 0.57; non-adjusted M = 12.35).

Table 5. MANCOVAs and Significant ANCOVA Follow-Up Findings for Health-Related Functioning Outcomes

	MANCOVA	ANCOVA	Effect Size	Non-Risk *M* (SD)	Risk *M* (SD)
Race/Ethnicity	*F* (5, 43) = 1.16		.12		
Health Insurance	*F* (5, 42) = 1.96		.19		
		UTI[a]: *F* (1, 87) = 5.06*	.06	0.69 (.43)	0.46 (.42)
Parent Education	*F* (5, 43) = 0.40		.04		
Parent Employment	*F* (5, 43) = 0.58		.06		
Parent Occupation	*F* (5, 41) = 1.75		.18		
Parent Immigrant Status	*F* (3, 37) = 0.66		.08		
Parent Language	*F* (3, 43) = 1.49		.09		
Family Structure	*F* (5, 42) = 0.89		.12		
Family Income-to-Needs	*F* (5, 41) = 2.71*		.25		
		UTI[a]: *F* (1, 82) = 4.87*	.06	0.69 (.43)	0.45 (.36)
		Pain[a]: *F* (1, 65) = 8.58**	.12	0.57 (.84)	1.30 (.85)
Zip Code Income	*F* (5, 43) = 1.12		.12		

Note. Due to missing data and the use of listwise deletion, *n's* range from 46 to 52 across MANCOVAs and from 70 to 92 across ANCOVAs. Each MANCOVA included attention problems body mass index percentile, sleep disturbances, lifetime number of urinary tract infections (UTIs), pain, and medical adherence. All analyses controlled for age, IQ, and condition severity. Partial eta squared is reported as an effect size estimate. Please see main document for explanation of Non-Risk and Risk categorization.
[a] Variables were log transformed to correct for skewness *$p < .05$, ** $p < .01$, ***$p < .001$.

In addition, for health insurance, while the multivariate analysis was *not* significant, there was a significant univariate finding for number of lifetime UTIs. Contrary to hypotheses, follow-up univariate analyses revealed a significant difference in number of lifetime UTIs, in that youth without private health insurance had significantly *less* UTIs (*M* = 0.46; non-adjusted *M* = 6.92) compared to youth with private health insurance (*M* = 0.69; non-adjusted *M* = 4.00). No other significant results were found for health-related functioning (*p’s* > .05).

Refer to Table 6 for results related to neuropsychological functioning. There was a significant difference based on race/ethnicity. Contrary to hypotheses, univariate follow-up analyses revealed a significant difference in both attention problems and executive function problems, in that non-Caucasian youth had significantly *fewer* attention (*M* = -0.12) and executive functioning (*M* = 1.64) problems compared to Caucasian youth (*M*’s = 0.04 and 1.71, respectively). There was also a significant difference based on health insurance. Contrary to hypotheses, univariate follow-up analyses revealed a significant difference in attention problems, in that youth without private health insurance had significantly *fewer* attention problems (*M* = -0.10) compared to youth with private insurance (*M* = -0.01). A significant difference was found based on parent education. Contrary to hypotheses, univariate follow-up analyses revealed a significant difference in both attention problems and executive function problems, in that youth with non-college educated parents had significantly *fewer* attention (*M* = -0.11) and executive functioning (*M* = 1.64) problems compared to youth with a college-educated parent (*M*’s = 0.05 and 1.73, respectively). Consistent with hypotheses, univariate follow-up analyses also revealed a significant difference in academic achievement, in that youth with non-college educated parents (*M* = 85.80) had significantly lower academic achievement compared to youth with a college educated parent (*M* = 100.70). Lastly, a significant difference was found based on parent occupation. Contrary to hypotheses, univariate follow-up analyses revealed a significant difference in both attention problems and executive function problems, in that youth with parents who have an occupation of lower status had significantly *fewer* attention (*M* = -0.11) and executive functioning (*M* = 1.65) problems compared to youth not at risk (*M*'s = 0.01 and 1.69, respectively).

In addition, while the multivariate analysis was *not* significant for parent employment, parent immigrant status, and parent language, there were significant univariate findings. Specifically, consistent with hypotheses, univariate follow-up analyses revealed a significant difference in academic achievement based on parent employment, in that youth with parents who were not employed full-time had significantly lower academic achievement (*M* = 81.48) compared to youth with parents who were employed full-time (*M* = 95.19). Contrary to hypotheses, univariate follow-up analyses revealed a significant difference in both attention problems and executive function problems based on parent immigrant status, in that youth with an immigrant parent had significantly *fewer* attention (*M* = -0.19) and executive functioning (*M* = 1.60) problems compared to youth not at risk (*M*'s = 0.02 and 1.70, respectively). Contrary to hypotheses, univariate follow-up analyses also revealed a significant difference in both attention problems and executive function problems based on parent language, in that youth with parents who did not speak English had significantly *fewer* attention (*M* = -0.24) and executive functioning (*M* = 1.57) problems compared to youth not at risk (*M*'s = 0.02 and 1.71, respectively). No other significant results were found for neuropsychological functioning (*p's* > .05).

Table 6. MANCOVAs and Significant ANCOVA Follow-Up Findings for Neuropsychological Functioning Outcomes

	MANCOVA	ANCOVA	Effect Size	Non-Risk *M* (SD)	Risk *M* (SD)
Race/Ethnicity	*F* (3, 116) = 3.68*		.09		
		Att: *F* (1, 124) = 8.36**	.06	0.04 (0.83)	–0.12 (0.66)
		EF: *F* (1, 124) = 6.59*	.05	1.71 (0.32)	1.64 (0.30)
Health Insurance	*F* (3, 112) = 2.84*		.07		
		Att: *F* (1, 118) = 3.94*	.03	–0.01 (0.78)	–0.10 (0.73)
Parent Education	*F* (3, 114) = 5.06**		.12		
		Att: *F* (1, 120) = 5.64*	.05	0.05 (0.81)	–0.11 (0.71)
		EF: *F* (1, 120) = 6.62*	.05	1.73 (0.30)	1.64 (0.30)
		AA: *F* (1, 120) = 8.67**	.07	100.70 (15.71)	85.80 (19.69)
Parent Employment	*F* (3, 115) = 1.81		.05		
		AA: *F* (1, 117) = 4.71*	.04	95.19 (18.48)	81.48 (19.16)
Parent Occupation	*F* (3, 110) = 3.76*		.09		
		Att: *F* (1, 116) = 9.32**	.07	0.01 (0.74)	–0.11 (0.76)
		EF: *F* (1, 116) = 5.61*	.05	1.69 (0.26)	1.65 (0.34)
Parent Immigrant Status	*F* (3, 94) = 1.54		.05		
		Att: *F* (1, 98) = 4.40*	.04	0.02 (0.80)	–0.19 (0.51)
		EF: *F* (1, 98) = 3.95*	.04	1.70 (0.31)	1.60 (0.22)
Parent Language	*F* (3, 116) = 1.49		.04		
		Att: *F* (1, 124) = 6.53*	.05	0.02 (0.80)	–0.24 (0.54)
		EF: *F* (1, 124) = 7.77**	.06	1.71 (0.32)	1.57 (0.28)
Family Structure	*F* (3, 112) = 0.62		.02		
Family Income-to-Needs	*F* (3, 104) = 0.80		.02		
Zip Code Income	*F* (3, 116) = 0.43		.01		

Note. Due to missing data and the use of listwise deletion, *n's* range from 101 to 123 across MANCOVAs and from 103 to 129 across ANCOVAs. Each MANCOVA included attention problems (Att; *z* score), executive function problems (EF; mean score), and academic achievement (AA; standard score). All analyses controlled for age, IQ, and condition severity. Partial eta squared is reported as an effect size estimate. Please see main document for explanation of Non-Risk and Risk categorization. *$p < .05$, ** $p < .01$, ***$p < .001$.

Lastly, there were no significant multivariate or univariate findings for psychosocial functioning outcomes (*p's* > .05).

Objective 2

The second objective was to examine the association between the *cumulative* effect of sociodemographic risk (i.e., cumulative risk) and youth health-related, neuropsychological, and psychosocial functioning, as moderated by age, all at Time 1. Analyses controlled for IQ and condition severity. It was hypothesized that greater cumulative risk would be associated with poorer health-related, neuropsychological, and psychosocial functioning concurrently, and these associations will vary based on age, in that they would be stronger for older youth. Consistent with hypotheses, results revealed that higher cumulative risk was found to be associated with more pain ($b = .12$, $SE = .06$, $\beta = .33$, $t = 2.13$, $p < .05$, $\Delta R^2 = .07$). However, contrary to hypotheses, higher cumulative risk was found to be associated with *fewer* lifetime UTI's ($b = -.04$, $SE = .02$, $\beta = -.23$, $t = -2.06$, $p < .05$, $\Delta R^2 = .04$), *less* attention problems ($b = -.08$, $SE = .03$, $\beta = -.29$, $t = -2.73$, $p < .01$, $\Delta R^2 = .07$), and *less* executive function problems ($b = -.03$, $SE = .01$, $\beta = -.27$, $t = -2.42$, $p < .05$, $\Delta R^2 = .06$. In addition, there were no significant interactions between cumulative risk and age.

Objective 3

The third objective was to examine SB-related family stress at Time 2 as a mediator of the longitudinal association between cumulative risk and sociodemographic factors at Time 1, and youth health-related, neuropsychological, and psychosocial functioning at Time 3. Hayes' PROCESS v2.16 statistical software was used to conduct bootstrapping analyses. Individual mediation models were run for each independent and dependent variable, as is recommended when using PROCESS (Hayes, 2013). Analyses controlled for youth age, IQ, condition severity, and the dependent variable at Time 1. It was hypothesized that individual sociodemographic factors characterized by risk and cumulative risk would predict greater SB-related family stress, which would, in turn, predict poorer youth health-related, neuropsychological, and psychosocial functioning.

Refer to Table 7 for results of significant indirect mediation models. Results revealed significant indirect mediation models for models predicting BMI, sleep disturbances, UTIs, attention problems, academic achievement, internalizing symptoms, and HRQOL. First, SB-related family stress mediated the associations between parent education and parent language predicting BMI. Specifically, sociodemographic risk (parents without a college education; parents whose preferred language is not English) predicted *less* SB-related family stress (contrary to hypotheses), and *less* family stress predicted higher BMI (contrary to hypotheses). SB-related family stress also mediated the associations between cumulative risk, race/ethnicity, health insurance, parent education, and parent immigrant status predicting sleep disturbances. Specifically, sociodemographic risk (non-Caucasian youth; youth without private insurance; parents without a college education; immigrant parents) and greater cumulative risk predicted *less* SB-related family stress (contrary to hypotheses), and *less* family stress predicted fewer sleep disturbances (consistent with hypotheses). SB-related family stress mediated the association between parent occupation predicting UTIs. Specifically, sociodemographic risk (parents with occupations of lower status) predicted *less* SB-related family stress (contrary to hypotheses), and *less* SB-related family stress predicted fewer UTIs (consistent with hypotheses).

Table 7. Significant Indirect Mediation Models of Cumulative Risk and Sociodemographic Factors at Time 1 as Predictors of Health-Related, Neuropsychological, and Psychosocial Functioning at Time 3, as Mediated by Spina Bifida-Related Family Stress at Time 2

Independent Variable Dependent Variable	Path A		Path B		Path C' Direct Effect		Path C Total Effect		Indirect Effect				Effect Size
	Coeff.	*SE*	*Coeff.*	*SE*	*Coeff.*	*SE*	*Coeff.*	*SE*	*Coeff.*	*SE*	95% CI Lower	95% CI Upper	
BMI													
Parent Education	–0.34*	0.15	–16.19	9.63	3.27	8.71	8.79	8.29	5.52	4.18	0.49	18.61	.22
Parent Language	–0.60*	0.22	–16.40	9.88	3.72	13.69	13.48	12.70	9.76	7.37	0.47	31.75	.39
Sleep Disturbances													
Cumulative Risk	–0.08**	0.03	0.22**	0.07	0.04**	0.02	0.02	0.02	–0.02	0.01	–0.04	–0.00	–.07
Race/Ethnicity	–0.36*	0.14	0.18*	0.07	0.11	0.08	0.04	0.08	–0.07	0.04	–0.19	–0.01	–.25
Health Insurance	–0.47**	0.13	0.20*	0.07	0.13	0.08	0.04	0.07	–0.09	0.05	–0.23	–0.03	–.33
Parent Education	–0.30*	0.14	0.20**	0.07	0.20**	0.07	0.14	0.07	–0.06	0.04	–0.16	–0.01	–.23
Parent Immigrant	–0.41**	0.41	0.15*	0.07	0.01	0.08	–0.05	0.08	–0.06	0.04	–0.18	–0.01	–.23
UTIs													
Parent Occupation	–0.50*	0.23	0.31	0.16	–0.09	0.20	–0.24	0.20	–0.15	0.11	–0.50	–0.01	–.34
Attention Problems													
Cumulative Risk	–0.08*	0.03	0.33*	0.13	–0.01	0.03	–0.03	0.03	–0.02	0.02	–0.08	–0.00	–.05
Parent Immigrant	–0.41*	0.18	0.29*	0.13	–0.16	0.16	–0.28	0.16	–0.12	0.08	–0.31	–0.00	–.27
Academic Achievement													
Zip Code Income	–0.34*	0.15	–3.47*	1.55	–3.87*	1.76	–2.69	1.74	1.17	0.85	0.09	3.59	.20
Internalizing Symptoms													
Cumulative Risk	–0.07*	0.03	0.41	0.21	0.05	0.04	0.02	0.04	–0.03	0.02	–0.08	–0.00	–.04
Health Insurance	–0.38**	0.13	0.32	0.21	–0.03	0.22	–0.15	0.21	–0.12	0.10	–0.44	–0.00	–.17
Parent Occupation	–0.32*	0.14	0.44*	0.20	0.38	0.21	0.23	0.21	–0.14	0.09	–0.38	–0.02	–.20
Parent Immigrant	–0.34*	0.14	0.36	0.21	0.10	0.23	–0.03	0.22	–0.12	0.08	–0.34	–0.02	–.17
HRQOL													
Cumulative Risk	–0.07*	0.03	–0.27**	0.10	–0.06**	0.02	–0.04	0.02	0.02	0.01	0.00	0.05	.05

Note. Due to missing data and the use of listwise deletion, *n's* range from 38 to 62 across models. BMI = body mass index percentile. UTI = lifetime number of urinary tract infections. *Coeff.* = estimated effect coefficient. *SE* = standard error. Path A is the direct effect of the independent variable (cumulative risk or sociodemographic factor) on the mediating variable (spina bifida-related family stress). Path B is the direct effect of the mediating variable (spina bifida-related family stress) on the outcome variable (health-related or psychosocial functioning), while controlling for the independent variable. Patch C' is the direct effect of the independent variable on the outcome variable, while controlling for the mediating variable. Path C is the total effect of the independent variable on the outcome variable. Partially standardized indirect effect coefficients are reported as estimates of effect size. All analyses controlled for age, IQ, and condition severity. $^{**}p<.01$, $^{*}p<.05$

SB-related family stress mediated the association between cumulative risk and parent immigrant status predicting attention problems. Specifically, sociodemographic risk (immigrant parents) and greater cumulative risk predicted *less* SB-related family stress (contrary to hypotheses), and *less* SB-related family stress predicted fewer attention problems (consistent with hypotheses). SB-related family stress mediated the association between zip code income predicting academic achievement, in that sociodemographic risk (living in an area of lower income) predicted *less* SB-related family stress (contrary to hypotheses), and *less* SB-related family stress predicted higher academic achievement (consistent with hypotheses). SB-related family stress mediated the association between cumulative risk, health insurance, parent occupation, and parent immigrant status predicting internalizing symptoms. Specifically, sociodemographic risk (youth without private insurance; parents with occupations of lower status; immigrant parents) and greater cumulative risk predicted *less* SB-related family stress (contrary to hypotheses), and *less* SB-related family stress predicted fewer internalizing symptoms (consistent with hypotheses). Lastly, SB-related family stress mediated the association between cumulative risk predicting HRQOL. Specifically, greater cumulative risk predicted *less* family stress (contrary to hypotheses), and *less* SB-related family stress predicted greater HRQOL (consistent with hypotheses).

CHAPTER FIVE

DISCUSSION

While families of youth with SB have demonstrated significant resilience (e.g., Lennon et al., 2015), they are also at risk for experiencing challenges in multiple domains (e.g., Holmbeck & Devine, 2010). Indeed, research has shown that youth with SB are at risk for experiencing poor health-related, neuropsychological, and psychosocial functioning, especially when compared to typically-developing youth (e.g., Dennis et al., 2006; Holmbeck et al., 2003; Liptak et al., 2015). While many domains have been examined as predictors of these outcomes (e.g., family functioning), one area that has not been sufficiently investigated is understanding the impact of sociodemographic factors. This is a crucial area for research given the pervasive health disparities that exist in the US and around the world, with pediatric chronic illness groups like SB being especially at risk (AAP, 2010). A few studies have found that sociodemographic factors such as insurance, household income, and SES explain variance in bladder continence, mobility, cognitive processes, and psychosocial adjustment among youth with SB (Holmbeck et al., 2003; Schechter et al., 2015; Wohlfeiler et al., 2008). However, this area of research is complicated by the lack of clarity and consistency among conceptual and methodological approaches used across studies (Cheng et al., 2015). Importantly, understanding *why*, or the processes through which, sociodemographic factors impact outcomes among youth with SB is just as important as understanding *if* they do. Thus, the current study sought to expand upon the limited understanding of how sociodemographic factors are associated with *health-related*, *neuropsychological*, and *psychosocial functioning* among youth with SB, and to understand the mechanisms and conditions through which these associations occur.

In summary, some hypotheses were supported while others were not. For Objective 1, consistent with hypotheses, it was discovered that youth with SB characterized by sociodemographic risk (based on family income-to-needs) reported higher pain and (based on parent education and parent employment) lower academic achievement. Contrary to hypotheses, youth with SB characterized by sociodemographic risk (based on health insurance and family income-to-needs) reported *fewer* lifetime UTIs. Further, youth characterized by sociodemographic risk across several factors (race/ethnicity, health insurance, parent education, parent occupation, parent immigrant status, and parent language) were reported to have *fewer* attention and executive function problems. Surprisingly, no other significant differences were found among risk and non-risk groups, including for any psychosocial functioning outcomes. For Objective 2, consistent with hypotheses, higher cumulative risk was found to be associated with more pain. However, contrary to hypotheses, higher cumulative risk was found to be associated with *fewer* lifetime UTIs, and *fewer* attention and executive function problems. In addition, age did *not* moderate the associations between cumulative risk and outcomes. Finally, for Objective 3, SB-related family stress was found to mediate the relation between cumulative risk and individual sociodemographic factors and several outcomes, namely, BMI, sleep disturbances, UTIs, attention problems, academic achievement, internalizing symptoms, and HRQOL. Notably, results revealed *indirect-only* mediation models. Importantly, and contrary to hypotheses, sociodemographic risk and cumulative risk predicted *lower* SB-related family stress across all models. However, with the exception of BMI, SB-related family stress did, in turn, predict outcomes in the expected direction. For example, lower SB-related stress predicted fewer sleep disturbances and higher HRQOL.

Overall, results highlight certain sociodemographic factors and cumulative risk are more predictive of outcomes than others, and certain outcomes are more impacted by sociodemographic factors than others. These associations seem to exist for youth at different ages/developmental stage, and constructs like SB-related family stress play an important role in how these associations unfold over time.

Differences in Outcomes between Risk and Non-Risk Groups

The first objective of this study was to examine differences in health-related, neuropsychological, and psychosocial functioning between youth who are and are not characterized by risk for each sociodemographic factor at Time 1. First, among health-related functioning outcomes, the risk and non-risk groups did not differ on BMI, sleep disturbances, or medical adherence. It is surprising that no differences were observed for BMI given that past research has found that among typically-developing youth, those who are racial/ethnic minorities, from low-income families, or who have parents with less than high school educations are more likely to have higher BMIs and to be obese (Frederick, Snellman, & Putnam, 2014). It is important to recognize that there may be limitations to the BMI data collected in the present study, in that height and weight measurements are often not routinely assessed at home or during clinic visits among youth with physical disabilities (McPherson, Swift, Yung, Lyons, & Church, 2013). One study found that among a sample of 180 youth with SB, only 35% had their height and weight routinely assessed at clinic visits, but of those who did, 24% were classified as overweight and 18% were classified as obese (41.3% were either overweight or obese based on their BMI; McPherson et al., 2013). The present study used parent-report of height and weight, unless it were missing, in which cases medical chart data was used. It is possible that most parents are reporting on the height and weight measurements that were most recently reported to them during their child's last clinic visit, which, according to research, may not have been recent. Further, it is also surprising that there were no group differences in sleep disturbances, given a past study found that lower SES predicted increasing sleep disturbances over a 10-year period (Murray et al., 2016). Perhaps the *accumulation of risk over time* is a better predictor of sleep quality in the SB population. Lastly, risk and non-risk groups did not significantly differ on medical adherence. Given the complex medical regimens that youth with SB are often tasked with, it could be considered encouraging to find that youth who may be under resourced (e.g., due to low income, low education) are not significantly *less* adherent to SB medical regimens compared to youth are not under resourced. Still, previous research (using data from the larger study from which the present study is drawn) has found non-adherence rates to range from 1.3% to 42.7%, suggesting non-adherence is a concern within this entire sample of youth with SB (Psihogios, Kolbuck, & Holmbeck, 2015).

Consistent with hypotheses, it was discovered that youth with SB from families who had a lower income-to-needs ratio reported higher pain. It has been well-documented that socioeconomic disadvantage is associated with an increased risk of pain among community and medical samples of *adults* worldwide (Poleschuck & Green, 2008). For the most part, this has also been shown to be true among typically-developing youth and youth with chronic illnesses, but inconsistencies in the literature exist (King et al., 2011). Among youth with SB, pain has been described as more prevalent and pertinent to psychosocial health than what was previously believed, and it has been found to predict outcomes such as social activity involvement (Essner, Murray, & Holmbeck, 2014).

Contrary to hypotheses, youth with SB from families who had a lower income-to-needs ratio and youth without private health insurance reported *fewer* lifetime UTIs. This is surprising given that a previous study found that those without private insurance were more likely to have bladder incontinence (Schechter et al., 2015). Notably, the current study used primarily parent-report of UTIs, and only pulled data from medical charts in cases where parent-report data were missing. Schechter and colleagues (2015) used data collected through a national registry. Parents may be inaccurate reporters of their child's lifetime number of UTIs, as past research has found variable evidence about the accuracy of parent-report of child health history (Pless & Pless, 1995; Schwarz, Monti, Savelli-Castillo, & Nelson, 2004). Or, parents at sociodemographic risk may be less vigilant to detecting UTIs, leading to under-reporting of lifetime numbers. The relation between income, insurance, and urological function in youth with SB must be further examined in the future, because urological issues can be a significant source of morbidity and mortality, and are implicated as a cause of death in almost a third of patients with SB (Oakeshott, Hunt, Poulton, & Reid, 2010).

Second, significant differences were found between risk and non-risk groups for each neuropsychological outcome. Consistent with hypotheses, youth whose parents had less than a college education and youth whose parents were not employed full-time had lower academic achievement. This is consistent with a past study that found that youth with SB from low SES households (measured by an education and occupation composite) had lower academic performance (Holmbeck et al., 2003). This is also consistent with the child development literature among typically-developing youth, which has shown parent education to be a robust predictor of academic performance (Davis-Kean, 2005).

Contrary to hypotheses, youth characterized by risk across several factors (i.e., youth who were non-Caucasian, without private health insurance, had parents with less than a college degree, had parents of a lower occupation status, had a parent who was an immigrant, and had parents whose preferred language was not English) were reported to have *fewer* attention problems. The same applied for executive functioning problems, except there were no differences based on health insurance. Attention and executive functioning were measured by parent- and teacher-report of these skills as observed in everyday life. Interestingly, there are some conflicting findings in the literature on sociodemographic factors, attention, and executive function problems among typically-developing youth. Specifically, studies have found ADHD *diagnoses* as reported by parents to be higher among low-income youth and youth without private insurance (Pastor, Reuben, Duran, & Hawkins, 2015), and ADHD *symptoms* and executive dysfunction as reported by parents and teachers to be higher among ethnic minority youth, youth from lower income families, and youth whose parents are of lower education and employment status (Martel, 2013). In contrast, and more in line with the present study’s findings, other studies have found ADHD *diagnoses* as reported by parents and medical charts are higher among Caucasian youth (Coker et al., 2016; Getahun et al., 2013; Pastor et al., 2015) and high-income youth (Getahun et al., 2013), presumably due to biases in referral for assessment and treatment. It could be that the parents and teachers of youth at sociodemographic risk have lower expectations for attention and executive function skills, thus not accurately identifying problems in everyday life. Given that all youth with SB are at risk for attention and executive function problems (Copp et al., 2015), more research is needed to understand these findings. Examining whether sociodemographic factors are associated with *performance-based* measures of attention and executive functioning may be particularly informative (Miranda, Colomer, Mercader, Fernandez, & Presentacion, 2015).

Lastly, no significant differences were found between risk and non-risk groups on psychosocial functioning outcomes (internalizing symptoms, externalizing symptoms, social adjustment, or quality of life). This was surprising given past research on youth with SB has found differences in social competence and externalizing symptoms between Caucasian and Hispanic youth, and differences in social problems based on SES (Holmbeck et al., 2003; Papadakis et al., 2018).

Associations between Cumulative Risk and Outcomes

The second objective of this study was to examine the association between the *cumulative* effect of sociodemographic risk (i.e., *cumulative* risk) and youth health-related, neuropsychological, and psychosocial functioning, as moderated by age, all at Time 1. As explained previously, cumulative risk was calculated by dichotomizing 10 sociodemographic factors into risk and non-risk groups (see Figure 1). Descriptive statistics revealed that participants in this study had, on average, 3.26 risk factors. Further, 49.5% of participants had 2 or less risk factors, and 77.3% had 5 or less risk factors. Based on the considerable body of research on cumulative risk (e.g., Sameroff, 2000), it was hypothesized that those with higher cumulative risk (i.e., more individual risk factors) would be more likely to have adverse outcomes. However, cumulative risk was association with more pain, but, interestingly, it was also associated with *fewer* lifetime UTI’s and *less* attention and executive function problems. These results largely reflect the findings that were revealed through Objective 1 analyses.

Further, age did not significantly moderate the associations between cumulative risk and outcomes. This suggests that the relations between cumulative risk and pain, UTIs, attention problems, and executive function problems does not vary whether youth are as young as 8 years old or as old as 15 years. There is reason to suspect that it would vary, based on what developmental psychopathology literatures tells us about the impact of the timing of cumulative risk (Appleyard et al., 2005; Sameroff, 2000). The moderation analyses in the present study tested whether the *timing* of risks (e.g., risk when at age 8 compared to risk when at age 9) impacted how risk and outcomes are related; analyses did not test the *chronicity* (e.g., being at risk for 1 year compared to 10 years) or *change* of risk (e.g., increases in risk) overtime, which have also been shown to be strong predictors of outcomes (Atkinson et al., 2015; Cundiff, Boylan, Pardini, & Matthews, 2017). This may be an area for further exploration. More may need to be understood about how pain, UTIs, attention, and executive function problems vary across development for youth with SB.

SB-Related Family Stress as a Mediator of Risk and Outcomes

The third objective was to examine SB-related family stress at Time 2 as a mediator of the longitudinal association between cumulative risk and sociodemographic factors at Time 1, and youth health-related, neuropsychological, and psychosocial functioning at Time 3. While many significant indirect-only mediation models were revealed, the directions of the effects were not entirely consistent with what was expected. For each specific sociodemographic factor and cumulative risk, higher risk was found to predict *less* SB-related family stress two years later.

This is surprising given that literature on typically-developing youth has found indicators such as income, SES, and poverty to be consistently linked to higher levels of stress (Chen & Miller, 2013; Evans, 2004).

Past research on youth with SB has not examined whether *SB-related* family stress varies based on sociodemographic factors. However, one past study compared youth with SB to typically-developing youth and discovered the following about *stress related to life events*: parents of youth with SB reported similar levels of stress regardless of their SES (determined by a parent occupation and education composite), whereas parents of comparison youth reported to have higher levels of stress at lower levels of SES (Jandasek et al., 2009). Stress habituation is an adaptive process where one desensitizes to stress after repeated exposure (Herman, 2013). It could be that having a child with a lifelong chronic illness leads to parents' habituation to stress. Further, perhaps parents who face chronic challenges due to their sociodemographic status also habituate to stress, and are less sensitized to it compared to families who have not had such exposure.

Counter-intuitive findings like the one found for SB-related family stress have been found in past studies on youth with SB. For example, a study examining differences between Caucasian and Hispanic youth with SB found there were many ways in which Hispanic youth were doing similarly well or better compared to Caucasian youth (Papadakis et al., 2018), despite other research that would have suggested otherwise. The present study's findings suggest that there may be other variables (e.g., coping strategies) that explain why families of youth with SB who are, presumably, less advantaged due to their education level, income, immigrant status, and so forth, are actually experiencing *less* stress related to caring for a child with SB. It could be that families possess strengths that are mitigating or eliminating the adverse impact of risks.

Chen and Miller (2013) have theorized about "shift-and-persist" characteristics that benefit families who face socioeconomic adversity. They propose that these families are confronted with repeated, unpredictable, and uncontrollable life events and competing demands. Because they may have limited options for problem-solving, they instead "shift" by adjusting their response to stressors in a way that is consistent with what other scholars have termed secondary control coping (e.g., acceptance, cognitive restructuring, positive thinking, distraction; Connor-Smith, Compas, Wadsworth, Thomsen, & Saltzman, 2000). Secondary control coping has been found to be adaptive in the face of challenges that are unchangeable or cannot be problem-solved, such as those presented by sociodemographic adversity (e.g., not being able to change your occupation, education level, or income level without significant time and resources; Santiago & Wadsworth, 2009) or challenges presented by a chronic illness (e.g., not being able to change the fact that one's child has a complicated medical regimen). When applied to the current study's findings, these theories suggest that families of youth with SB characterized by sociodemographic risk may be using adaptive forms of coping that mitigate the stress they experience over time.

Further, the "persist" aspect of Chen and Miller's (2013) theory refers to the ability to endure adversity by finding meaning in difficult situations, having optimism about the future, and maintaining a focus on long-term goals. This is sometimes referred to as "meaning-focused" coping and is believed to help socioeconomically disadvantaged families be resilient to daily stressors by maintaining hope and optimism. Interestingly, research has found that parents of youth with SB are optimistic in their expectations for their children's development (Holbein et al., 2017). Together, this suggests that meaning-making, optimism, and hope, are strength-based areas that should be further researched in families of youth with SB, especially those at sociodemographic risk.

While the finding that greater risk predicted *less* SB-related family stress was counter-intuitive, the associations between SB-related family stress and outcomes were in the expected directions, in that, with the exception of BMI, greater SB-related family stress led to poorer functioning across outcomes, namely, sleep disturbances, UTIs, attention problems, academic achievement, internalizing symptoms, and HRQOL. This highlights how SB-related family stress can impact youth overtime across multiple domains: health-related, neuropsychological, and psychosocial.

Across all significant mediation models, the total effects (i.e., the combined impact of both risk and SB-related family stress on outcomes) were not significant, and only a few direct effects (i.e., the impact of risk on outcomes, controlling for SB-related family stress) were significant. This highlights the utility of using boot strapping methods to test for indirect-only mediation effects (Hayes, 2009), as by doing so, it revealed a clearer understanding of the pathways through which sociodemographic risk can impact outcomes among youth with SB over time.

Conclusions across Findings

Past research has suggested that cumulative risk variables are better predictors of child outcomes than single, isolated risk factors, because cumulative risk more accurately reflects the natural covariation of many childhood risk factors that are often disproportionally allocated in society, such as among poor and racial/ethnic minority groups (Atkinson et al., 2015; Doan et al., 2012; Evans, 2003; Evans et al., 2007; Sameroff, 2000). When evaluating the utility of examining cumulative risk compared to single indicators of sociodemographic risk, comparing results from Objectives 1 and 2 suggests that cumulative risk did not necessarily reveal itself to be a more explanatory variable compared to examining sociodemographic risk variables individually. When comparing the effect sizes of the indirect-only mediation models in Objective 3, one can see that models containing cumulative risk as the independent variable had relatively lower (< .20) effect sizes compared to models with other individual sociodemographic factors as the independent variable. However, Objective 3 results also suggest that examining the effect of cumulative risk through mediating processes overtime is fruitful. For example, HRQOL was not found to be impacted by any individual sociodemographic factors or cumulative risk concurrently. However, mediation results revealed that higher cumulative risk predicted lower SB-related family stress two years later, and, in turn, that lower stress predicted higher HRQOL two years after that.

Results of the present study also highlight the nuanced relations that exist among the numerous sociodemographic factors and health-related, neuropsychological, and psychosocial outcomes examined in this study. Objective 1 results highlight how multiple indicators of sociodemographic risk explain differences in neuropsychological functioning outcomes, particularly attention and executive function problems, whereas there were few differences found among health-related outcomes and no differences found among psychosocial outcomes. Yet, outcomes such as BMI, sleep disturbances, internalizing symptoms, and HRQOL were indirectly predicted by the impact of risk on SB-related family stress overtime. Further, parent education and parent immigrant status were two sociodemographic factors that revealed differences in multiple outcomes, whereas other factors, such as family structure and zip code income, did not account for any differences. This highlights the importance of assessing the impact of a *variety* of sociodemographic factors on a *variety* of outcomes (Cheng et al., 2015).

An important take-away from the present study is that many findings were contrary to hypotheses. Namely, these findings revealed that youth characterized by sociodemographic risk were found to have *fewer* UTIs and *less* attention and executive function problems, and that sociodemographic risk was associated with *less* SB-related family stress. It is important to highlight that all of these outcomes were either parent-reported (UTIs and SB-related family stress) or parent- and teacher-reported (attention and executive function problems). Significant differences in the *expected* direction were for those outcomes that were *not* parent-reported, i.e., youth-reported pain and performance-based academic achievement. It may be that parents who are characterized by sociodemographic risk are less observant or sensitive to concerns such as UTIs, neuropsychological functioning, and SB-related family stress.

Still, these contrary findings suggest that, despite sociodemographic risks, youth with SB demonstrate significant resiliency. Literature on families of youth with SB supports a resilience-disruption view of functioning, in that while the presence of having a child with SB may disrupt normative family functioning in certain ways, these families are able to adapt and demonstrate considerable resilience (Costigan, Floyd, Harter, McClintock, 1997; Lennon et al., 2015). In other words, results suggest that a resilience-disruption view functioning that has been supported in the literature for all youth with SB (Lennon et al., 2015) can be applied specifically to youth with SB characterized by sociodemographic factors that may, in other domains, put them at risk.

Research has found that disparities in health outcomes exist among youth with a variety of chronic health conditions and disabilities, including cancer (Bemis et al., 2015), diabetes (Borschuck & Everheart, 2015), asthma (Chen et al., 2003), HIV/AIDS (Coscia et al., 2001), obesity (Fradkin et al., 2015), as well as cystic fibrosis, cerebral palsy, sickle cell disease, hemophilia, and traumatic brain injury (Berry et al., 2010; Mullins et al., 2011). These past studies have also highlighted that the impact is not the same across illness groups (Schechter et al., 2015). The objective of the present study was to understand how sociodemographic factors impact youth with SB in particular. This is important given that among individuals with SB, there are disparities in prevalence and incidence rates (Boulet et al., 2008), there is a significant economic burden placed on families managing lifelong intensive health care needs (Rofail et al., 2013), and given the overall complex nature of the condition and the numerous health-related, neuropsychological, and psychosocial challenges that may confront these youth. Without having a comparison sample, conclusions cannot be drawn about how findings from the present study are unique to the SB population. However, as the body of literature grows on health disparities among youth with SB and other pediatric chronic illness populations, and constructs and outcomes are examined in a similar manner across studies, comparisons can be drawn. Still, the present study established an excellent base from which to build from.

Strengths, Limitations, and Future Research

This study had several strengths. First, the current study was the first to attempt a comprehensive examination of how sociodemographic factors impact the health-related, neuropsychological, and psychosocial functioning among youth with SB. It attempted to address methodological weaknesses in research to date by examining ten different sociodemographic factors. Second, the study drew from sound theoretical models to examine a moderator (i.e., age) and mediator (i.e., SB-related family stress), in an effort to understand the conditions under which, and the mechanisms through which, the associations among constructs exist. Identifying the pathways and mechanisms though which sociodemographic factors impact youth outcomes is essential for identifying targets for intervention (Cheng et al., 2015). Third, the current study used multiple methods and reporters, which has been encouraged within research in general, and the field of SB research specifically (Holmbeck et al., 2006). Fourth, longitudinal data were used to examine associations over time, which allows for consideration of developmental changes in childhood and adolescence (Holmbeck et al., 2006).

However, there were several limitations to the current study that should be addressed in future work. First, the present study had missing data owing to item nonresponse, attrition, and protocol changes for youth who were 18 years or older at Time 3. The present study used listwise deletion, as is recommended when data is missing completely at random (Schafer & Graham, 2002). Still, this limited the sample size across analyses, thus limiting the power to detect significant findings. Most effect sizes were small (< .20), though some fell in the moderate range (between .20 and .39). Second, some constructs were measured using a composite of multiple reporters across the same or different measures. The internalizing symptoms composites at Times 1 and 3 (α's = .54 and .53, respectively) had Cronbach alpha values that were less than what is recommended (α > .60) for computing composite. Third, the literature on health disparities is complicated by the variability in how sociodemographic factors are defined, measured, and analyzed. While this study attempted to address methodological and theoretical weaknesses of past studies, it made conceptual and analytic decisions that may make generalizability of findings to other samples difficult. Specifically, dichotomization of sociodemographic factors into risk and non-risk categories was based on the literature (Evans, 2003; Rutter, 1993; Sameroff et al., 2004), in addition to the desire to balance group sizes. For example, the present study examined parent education by dichotomizing it into parents with less than a college education (risk) and parents with a college education or more (non-risk), and it could be argued that there are other ways to dichotomize such a variable (e.g., less than or more than a high school education). Further, categorizing racial/ethnic minority status as a "risk" fails to reflect that the risk is due to social determinants that are active in American culture today, and not necessarily race in and of itself. Lastly, the study takes a "risk" approach, when "promotive" or strengths-based approaches have also been suggested, and could be beneficial (Sameroff, 2000).

The literature would benefit from additional research on health disparities and the impact of sociodemographic factors among youth with SB. Future studies should attempt to address the limitations of the current study. This includes recruiting a large, diverse sample that is representative of the country at large. Further, future studies should consider assessing sociodemographic factors that were not examined in the present study, including access to health care, utilization of health care, perceived and objective health care quality, and health literacy. Our understanding of the present topic would be enhanced if future studies examined the course of illness progression and health over time, as a function of sociodemographic factors. Importantly, future research should attempt to extend the results of the present study and explore other variables that may explain the counter-intuitive findings of the present study. For example, understanding why youth characterized by sociodemographic risk were actually found to have *less* SB-related family stress. There may be strength-based constructs at play that would be important to assess for, including those mentioned earlier such as coping, optimism, and hope. Further, given that the findings that were contrary to hypotheses were found for constructs that were parent-reported, the literature would benefit from additional research that compared reports from parents, youth, teachers, health professionals, as well as medical chart, observational, and performance-based data.

Conclusions and Clinical Implications

It is hoped that findings from the proposed study will improve the lives of youth with SB by informing future research questions, and local and national policies aimed at improving outcomes among youth with SB. Importantly, the results of the current study have implications for delivering evidence-based, diversity-sensitive clinical care to youth with SB. It appears that, despite the evidence that suggests certain sociodemographic characteristics put youth at risk for poor outcomes, youth with SB in the current study who were characterized by such risks (e.g., low income) were found, in some ways, to have similar or better outcomes compared to youth not characterized by risk. This highlights that youth with SB have areas of resiliency that, if identified, can be used to promote better adjustment outcomes. Still, there are ways in which youth characterized by risk *were* more likely to have poorer outcomes, such as in the domains of pain and academic achievement. Youth would benefit from thoughtful and comprehensive clinical assessments of the sociodemographic factors that *may* put youth at risk for adverse outcomes. Importantly, health disparities are largely a function of social conditions, policies, and institutions, and while these arenas may be challenging to reform, they *can* be improved upon

(AAP, 2009; Cheng et al., 2015). Thus, using data from the present study to inform health care reform and social policies will benefit youth with spina bifida, as well as *all* children.

APPENDIX

QUESTIONNAIRE MEASURES AND MEDICAL CHART REVIEW FORM

3

[91]

ID # ____________

PDQ

1. Today's Date: ______________________________
Month Day Year

2. Are you this child's:
   1. ________ Mother
   2. ________ Father
   3. ________ Step-mother
   4. ________ Step-father
   5. ________ Adoptive mother
   6. ________ Adoptive father
   7. ________ Grandmother
   8. ________ Grandfather
   9. ________ Other Relation? ____________________

3. YOUR Date of Birth: ______________ YOUR Age: __________

4. YOUR Ethnicity/Race:
   1. ________ White
   2. ________ African-American
   3. ________ Hispanic
   4. ________ Asian
   5. ________ Other ____________________

5. Your SPOUSE'S/SIGNIFICANT OTHER'S Ethnicity/Race:

   1.________ White
   2.________ African-American
   3.________ Hispanic
   4.________ Asian
   5.________ Other ____________________

6. Your CHILD'S Date of Birth: ______________ Your CHILD'S Age: __________

7. Your CHILD'S Ethnicity/Race:
   1. ________ White
   2. ________ African-American
   3. ________ Hispanic
   4. ________ Asian
   5. ________ Other ____________________

8. Your CHILD'S Grade: ______________

Your CHILD'S School: ______________________________

Is this a public or private school? ________ Public ________ Private

9. Are you satisfied with your child's school placement? ________ Yes ________ No

If NO, why not? ______________________________

____

10. Please list the FIRST name, sex, and age of all other individuals <u>LIVING IN YOUR HOME</u>. Also, include their relationship to your child (for example, mother, father, step-father, mother's boyfriend, grandmother, brother, sister, <u>step</u>-brother, <u>half</u>-brother, cousin, <u>adopted</u>, etc.)

	FIRST NAME	SEX	AGE	RELATIONSHIP TO YOUR CHILD
1.				
2.				
3.				
4.				
5.				
6.				
7.				
8.				
9.				
10.				

**Please indicate if a sibling is a "step" or "half" sibling or adopted

11. Does your child have any brothers or sisters who are not living with you? If so, please list them:

	FIRST NAME	SEX	AGE	RELATIONSHIP TO YOUR CHILD	WHERE LIVING?
1.					
2.					
3.					
4.					

12. What is your <u>CURRENT</u> MARITAL STATUS (please circle one):
   a. **Married** to child's biological father/mother
   b. **Separated** from child's biological father/mother
   c. **Divorced** from child's biological father/mother and <u>not</u> remarried
   d. **Divorced** from child's biological father/mother and <u>remarried</u>
   e. **Divorced** from child's biological father/mother and currently living with a significant other
   f. **Divorced or separated** from child's stepfather/stepmother and <u>not</u> remarried
   g. **Divorced** from child's stepfather/stepmother and <u>remarried</u>
   h. **Widow or widower** and have <u>not</u> remarried
   i. **Widow or widower** and have <u>remarried</u>
   j. **Widow or widower** and currently living with a significant other
   k. **Never married** and currently living with child's biological father/mother
   l. **Never married** and currently living with a significant other
   m. **Never married**
   n. **Other** (please explain) ______________________________

13. Please indicate the years for all of the following that apply to you:

Year of first marriage (for example: 1989, 2002): ____________

Years of divorces: ____________ ____________ ____________ ____________

Years of remarriages: ____________ ____________ ____________ ____________

Year of death of spouse: ____________

14. How long have you and your current SPOUSE / SIGNIFICANT OTHER been married or living together?

____________________ Years

15. Check the highest level of education that you completed:

1. ________ some grade school
2. ________ finished grade school
3. ________ some high school
4. ________ finished high school
5. ________ business or technical school
6. ________ some college
7. ________ finished college
8. ________ attended graduate school or professional school after college
9. ________ received a professional degree
10. ________ I am currently enrolled in the following: ______________________________

16. Check the highest level of education that your SPOUSE / SIGNIFICANT OTHER completed:

1. ________ some grade school
2. ________ finished grade school
3. ________ some high school
4. ________ finished high school
5. ________ business or technical school
6. ________ some college
7. ________ finished college
8. ________ attended graduate school or professional school after college
9. ________ received a professional degree
10. ________ S/he is currently enrolled in the following: ______________________________

17. Check the highest level of education you think that your child will complete:

1. ________ some grade school
2. ________ finished grade school
3. ________ some high school
4. ________ finish high school
5. ________ business or technical school
6. ________ some college
7. ________ finish college
8. ________ attend graduate school or professional school after college
9. ________ receive a professional degree

18. What is your religion (if any)? ____

19. How important is religion in your life (please circle one)?
    a. Not at all important
    b. A little important
    c. Somewhat important
    d. Very important
    e. Extremely important

20. Are you a student? ___________ yes ______________ no

    If YES, are you a part-time student or a full-time student?

    ________ part-time student ________ full-time student

21. What is your current EMPLOYMENT status (please circle one)?
    a. Full-time homemaker (does not work outside the home)
    b. Retired
    c. On disability form work
    d. Employed part-time
    e. Employed full-time
    f. Other (please explain) ____

22. If you are EMPLOYED part-time or full-time, please describe your job:
    a. Where do you work? ____
    b. What kind of work do you do? ____
    c. How many hours per week do you work? _______________________________________
    d. At what time of day do you usually leave home to go to work (or to school)?

       _______________ (please specify a.m. or p.m.)
    e. At what time of day do you usually get home after work (or to school)?

       _______________ (please specify a.m. or p.m.)
    f. Would you say that you are satisfied with your current job?

       ___________ very satisfied
       ___________ satisfied
       ___________ moderately satisfied
       ___________ moderately dissatisfied
       ___________ dissatisfied
       ___________ very dissatisfied

23. Is your SPOUSE / SIGNIFICANT OTHER a student? __________ yes _________ no

    If YES, is s/he a part-time student or a full-time student?

    ________ part-time student ________ full-time student

24. What is your SPOUSE / SIGNIFICANT OTHER's current EMPLOYMENT status (please circle one)?

a. Full-time homemaker (does not work outside the home)
b. Retired
c. On disability form work
d. Employed part-time
e. Employed full-time
f. Other (please explain) ____________________

25. If your SPOUSE / SIGNIFICANT is EMPLOYED part-time or full-time, please describe his/her job:

a. Where does s/he work? ____________________
b. What kind of work does s/he do?

____

c. How many hours per week do s/he work? ____________________
d. At what time of day does s/he usually leave home to go to work (or to school)?

____________ (please specify a.m. or p.m.)

e. At what time of day does s/he usually get home after work (or to school)?

____________ (please specify a.m. or p.m.)

f. Would you say that s/he is satisfied with his/her current job?

__________ very satisfied
__________ satisfied
__________ moderately satisfied
__________ moderately dissatisfied
__________ dissatisfied
__________ very dissatisfied

26. What is your family's total yearly income?

1. ________ under $10, 000
2. ________ 10, 000-19,999
3. ________ 20, 000-29,999
4. ________ 30, 000-39,999
5. ________ 40, 000-49,999
6. ________ 50, 000-59,999
7. ________ 60, 000-69,999
8. ________ 70, 000-79,999
9. ________ 80, 000-89,999
10. ________ 90, 000-99,999
11. ________ 100, 000-109,999
12. ________ 110, 000-119,999
13. ________ 120, 000-129,999
14. ________ 130, 000-139,999
15. ________ 140, 000-149,999
16. ________ 150, 000-159,999
17. ________ 160, 000-169,999
18. ________ 170, 000-179,999
19. ________ 180, 000-189,999
20. ________ 190, 000-199,999
21. ________ over 200, 000

27. During the WEEK (Monday to Friday), how many hours do YOU spend with the child being discussed in this questionnaire, PER DAY, on average (when both of you are awake)?

    ____

28. During the WEEK (Monday to Friday), how many hours does your SPOUSE / SIGNIFICANT OTHER spend with your child, PER DAY, on average (when both of them are awake)?

    ____

29. During the WEEK (Monday to Friday), how many hours do your OTHER SIGNIFICANT CAREGIVERS (e.g., grandmother, nanny) spend with your child, PER DAY, on average (when both of them are awake)?

    ____

30. During the WEEKEND (Saturday and Sunday), how many hours do YOU spend with the child being discussed in this questionnaire, PER DAY, on average (when both of you are awake)?

    ____

31. During the WEEKEND (Saturday and Sunday), how many hours does your SPOUSE / SIGNIFICANT OTHER spend with your child, PER DAY, on average (when both of them are awake)?

    ____

32. During the WEEKEND (Saturday and Sunday), how many hours do your OTHER SIGNIFICANT CAREGIVERS (e.g., grandmother, nanny) spend with your child, PER DAY, on average (when both of them are awake)?

    ____

33. For the child being discussed in this questionnaire, please list the tasks around the house that you expect him/her to perform:

34. What tasks related to your child's spina bifida do you perform?

What tasks related to your child's spina bifida does your child perform?

35. My child is receiving special education/school services in the following areas (Please check ALL that apply):

________ Learning Disabilities resource class or help
________ Learning Disabilities self-contained class
________ Speech/Language resource class or help
________ Speech/Language self-contained class
________ Emotional/Behavioral resource class or help
________ Emotional/Behavioral self-contained class
________ Occupational/Physical Therapy
________ English as a Second Language (ESL)
________ Placement in a Bilingual Classroom…which language? ____________
________ Tutoring … what area? ______________________________
________ Other (please explain) ______________________________

36. Has the child being discussed in this questionnaire ever received mental health services (counseling)? ________ yes ________ no

37. What, if any, mental health diagnoses has your child been given (e.g., depression, anxiety)?

____

____

38. Has anyone else in your family ever received mental health services (counseling)?
________ yes ________ no

39. Has your child been diagnosed with Attention Deficit Hyperactivity Disorder?
________ yes ________ no

If YES, who diagnosed your child? ______________________________

40. Has your child ever had any of the following evaluations?

Psychological	________	yes	________	no
Neuropsychological	________	yes	________	no
Educational	________	yes	________	no
Speech/Language	________	yes	________	no
Occupational Therapy	________	yes	________	no
Physical Therapy	________	yes	________	no
Neurological (EEG, MRI)	________	yes	________	no

41. Has the child being discussed in this questionnaire had any serious medical problems (other than those related spina bifida) ________ yes ________ no

If YES, what were they? ______________________________________

____

Medical History and Adherence Questionnaire

1. What type of spina bifida does your child have?

   _____ lipomeningocele (lipo)
   _____ myelomeningocele (MM)
   _____ not sure

2. What is the level of your child's lesion?

   _____ sacral
   _____ lumbar
   _____ thoracic
   _____ not sure

3. Does your child have a shunt? yes _____ no _____

   a. IF YES, has your child's shunt been infected? yes _____ no _____
   b. IF YES, has your child had a shunt revision? yes _____ no _____
   c. IF your child's SHUNT HAS BEEN INFECTED, how many times? _____
   d. IF your child has had a SHUNT REVISION, how many times? _____

4. Does your child have seizures or take medication to prevent seizures?
   yes _____ no _____

5. Is your child able to do independent toileting?
   yes _____ no _____

6. Is your child on a catheterization schedule? yes _____ no _____

   a. If YES, does your child do the catheterization (check one)?

      _____ independently without reminding
      _____ independently with reminding
      _____ with partial assistance
      _____ with complete assistance

   b. Has your child ever had a bladder or urinary tract infection? yes _____ no _____

   c. How many times has your child had a bladder or urinary tract infection? _______

   d. Has your child had bladder stimulation? yes _____ no_____

7. Is your child on a bowel program?
yes _____ no _____

a. If YES, what type of bowel program (suppositories, diet, enemas, digital manipulation, etc.)?

____

____

____

b. If YOUR CHILD IS ON A BOWEL PROGRAM, does your child do this program (check one)?

_____ independently without reminding
_____ independently with reminding
_____ with partial assistance
_____ with complete assistance

c. Has your child had bowel stimulation? yes _____ no _____

8. Does your child use diapers? yes _____ no _____

a. If YES, where does your child use diapers (please check all that apply)?

_____ school
_____ home
_____ on outings
_____ all the time
_____ other? _______________________

9. Does your child use braces? yes _____ no _____

a. If YES, what type (please check all that apply)?

_____ ankle-foot
_____ knee-ankle-foot
_____ hip-knee-ankle-foot
_____ reciprocating brace
_____ full control brace
_____ swivel walker
_____ parapodium
_____ twister cables
_____ night splint
_____ back brace

10. Does your child use crutches? yes _____ no _____

11. Does your child use a walker? yes _____ no _____

a. If YES, where does your child use a walker (please check all that apply)?

_____ school
_____ home
_____ for long distance walking
_____ on outings
_____ all the time
_____ other? ______________________________

12. Does your child use a wheelchair? yes _____ no _____

a. If YES, where does your child use a wheelchair (please check all that apply)?

_____ school
_____ home
_____ for long distance travel
_____ on outings
_____ all the time
_____ other? ______________________________

13. If your child uses more than one mobility device, please write down the percentage of time that your child uses each device (please make sure that the percentages add up to 100%):

_____ % unassisted walking (no braces)
_____ % braces alone (no crutches or walker)
_____ % braces with crutches or walker
_____ % wheelchair
= 100 %

14. Please list your child's medications (include NAME OF MEDICATION, AMOUNT, HOW OFTEN TAKEN):

	Name of Medication	Amount	How Often Taken?
1.			
2.			
3.			
4.			
5.			
6.			
7.			
8.			
9.			
10.			

15. Please list your child's surgeries, since birth (include year of surgery, reason for surgery; examples include: shunt revision, shunt replacement, leg surgery, back surgery, tethered cord, etc.):

	Year of Surgery	Reason for Surgery
1.		
2.		
3.		
4.		
5.		
6.		
7.		
8.		
9.		
10.		
11.		
12.		
13.		
14.		
15.		

16. What changes have occurred in your child's health OVER THE PAST YEAR?

[103]

17. What type of health insurance does your child have?

____

18. In the past year, how many visits has your child had with a primary care physician (regular family doctor)? ______________

Please describe the reason for these visits: ______________________

____

____

19. In the past year, how many visits has your child had with a urologist? ______________

Please describe the reason for these visits: ______________________

____

____

20. In the past year, how many visits has your child had with a orthopedist? ______________

Please describe the reason for these visits: ______________________

____

____

21. In the past year, how many visits has your child had with a neurologist? ______________

Please describe the reason for these visits: ______________________

____

____

22. In the past year, how many visits has your child had with a physical or occupational therapist? (please specify which one)

____

Please describe the reason for these visits: ______________________

____

____

20

23. In the past year, on how many occasions has your child visited the emergency room? ______

Please describe the reason for these visits: ______________________________

____

____

24. In the past year, how many visits has your child had with any other type of health care professional? ______________________________

Type of health professional seen: ______________________________

____

Please describe the reason for these visits: ______________________________

____

____

25. In the past year, how many times has your child been hospitalized? ______________

Length of stay ______________________________

Please describe the reason for these hospitalizations: ____________________

____

____

Generational Status-P

Some families have lived in the United States for a very long time, whereas others may have only lived here for a short time. Below are some questions about your family background.

1. In what country were you born?____
2. If you were born in another country, how old were you when you immigrated to the United States? _________________
3. Have you ever lived anywhere outside of the United States? (Please circle one) **Yes / No**

   If so, where? ____

   If so, how long? ____
4. How long have you lived in the United States? _____________________________________
5. In what country was your mother born? ______________________________________
6. In what country was your father born? ______________________________________
7. How would you describe your ethnicity/culture of origin? (feel free to use more than one

   description) ____
8. From what country(ies) are your family ancestors? _________________________________

   ____

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ASEBA

Please print **CHILD BEHAVIOR CHECKLIST FOR AGES 6-18**

For office use only
ID# [106]

CHILD'S FULL NAME First Middle Last

CHILD'S GENDER ☐ Boy ☐ Girl

CHILD'S AGE

CHILD'S ETHNIC GROUP OR RACE

TODAY'S DATE Mo.______ Date ______ Yr. ______

CHILD'S BIRTHDATE Mo.______ Date ______ Yr. ______

GRADE IN SCHOOL ________

NOT ATTENDING SCHOOL ☐

Please fill out this form to reflect *your* view of the child's behavior even if other people might not agree. Feel free to print additional comments beside each item and in the space provided on page 2. ***Be sure to answer all items.***

PARENTS' USUAL TYPE OF WORK, even if not working now. *(Please be specific — for example, auto mechanic, high school teacher, homemaker, laborer, lathe operator, shoe salesman, army sergeant.)*

FATHER'S TYPE OF WORK ________________

MOTHER'S TYPE OF WORK ________________

THIS FORM FILLED OUT BY: (print your full name)

____

Your gender: ☐ Male ☐ Female

Your relation to the child:

☐ Biological Parent ☐ Step Parent ☐ Grandparent

☐ Adoptive Parent ☐ Foster Parent ☐ Other (specify)________

I. Please list the sports your child most likes to take part in. For example: swimming, baseball, skating, skate boarding, bike riding, fishing, etc.

☐ None

Compared to others of the same age, about how much time does he/she spend in each? / **Compared to others of the same age, how well does he/she do each one?**

	Less Than Average	Average	More Than Average	Don't Know	Below Average	Average	Above Average	Don't Know
a. ________	☐	☐	☐	☐	☐	☐	☐	☐
b. ________	☐	☐	☐	☐	☐	☐	☐	☐
c. ________	☐	☐	☐	☐	☐	☐	☐	☐

II. Please list your child's favorite hobbies, activities, and games, other than sports. For example: stamps, dolls, books, piano, crafts, cars, computers, singing, etc. (Do *not* include listening to radio or TV.)

☐ None

Compared to others of the same age, about how much time does he/she spend in each? / **Compared to others of the same age, how well does he/she do each one?**

	Less Than Average	Average	More Than Average	Don't Know	Below Average	Average	Above Average	Don't Know
a. ________	☐	☐	☐	☐	☐	☐	☐	☐
b. ________	☐	☐	☐	☐	☐	☐	☐	☐
c. ________	☐	☐	☐	☐	☐	☐	☐	☐

III. Please list any organizations, clubs, teams, or groups your child belongs to.

☐ None

Compared to others of the same age, how active is he/she in each?

	Less Active	Average	More Active	Don't Know
a. ________	☐	☐	☐	☐
b. ________	☐	☐	☐	☐
c. ________	☐	☐	☐	☐

IV. Please list any jobs or chores your child has. For example: paper route, babysitting, making bed, working in store, etc. (Include both paid and unpaid jobs and chores.)

☐ None

Compared to others of the same age, how well does he/she carry them out?

	Below Average	Average	Above Average	Don't Know
a. ________	☐	☐	☐	☐
b. ________	☐	☐	☐	☐
c. ________	☐	☐	☐	☐

Be sure you answered all items. Then see other side.

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1 South Prospect St., Burlington, VT 05401-3456
www.ASEBA.org

6-1-01 Edition - 201

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Please print. Be sure to answer all items.

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V. 1. About how many close friends does your child have? (Do *not* include brothers & sisters)
☐ None ☐ 1 ☐ 2 or 3 ☐ 4 or more

2. About how many times a week does your child do things with any friends outside of regular school hours? (Do *not* include brothers & sisters) ☐ Less than 1 ☐ 1 or 2 ☐ 3 or more

VI. Compared to others of his/her age, how well does your child:

	Worse	Average	Better	
a. Get along with his/her brothers & sisters?	☐	☐	☐	☐ Has no brothers or sisters
b. Get along with other kids?	☐	☐	☐	
c. Behave with his/her parents?	☐	☐	☐	
d. Play and work alone?	☐	☐	☐	

VII. 1. Performance in academic subjects. ☐ Does not attend school because ______________________

	Check a box for each subject that child takes	Failing	Below Average	Average	Above Average
	a. Reading, English, or Language Arts	☐	☐	☐	☐
Other academic subjects–for example: computer courses, foreign language, business. Do ***not*** include gym, shop, driver's ed., or other nonacademic subjects.	b. History or Social Studies	☐	☐	☐	☐
	c. Arithmetic or Math	☐	☐	☐	☐
	d. Science	☐	☐	☐	☐
	e. ______________________	☐	☐	☐	☐
	f. ______________________	☐	☐	☐	☐
	g. ______________________	☐	☐	☐	☐

2. Does your child receive special education or remedial services or attend a special class or special school?
☐ No ☐ Yes—kind of services, class, or school:

3. Has your child repeated any grades? ☐ No ☐ Yes—grades and reasons:

4. Has your child had any academic or other problems in school? ☐ No ☐ Yes—please describe:

When did these problems start? ______________________

Have these problems ended? ☐ No ☐ Yes–when?

Does your child have any illness or disability (either physical or mental)? ☐ No ☐ Yes—please describe:

What concerns you most about your child?

Please describe the best things about your child.

Be sure you answered all items.

Please print. Be sure to answer all items.

Below is a list of items that describe children and youths. For each item that describes your child ***now or within the past 6 months***, please circle the ***2*** if the item is ***very true or often true*** of your child. Circle the ***1*** if the item is ***somewhat or sometimes true*** of your child. If the item is ***not true*** of your child, circle the ***0***. Please answer all items as well as you can, even if some do not seem to apply to your child.

0 = Not True (as far as you know) **1 = Somewhat or Sometimes True** **2 = Very True or Often True**

0 1 2 1. Acts too young for his/her age
0 1 2 2. Drinks alcohol without parents' approval (describe): ______________________
0 1 2 3. Argues a lot
0 1 2 4. Fails to finish things he/she starts
0 1 2 5. There is very little he/she enjoys
0 1 2 6. Bowel movements outside toilet
0 1 2 7. Bragging, boasting
0 1 2 8. Can't concentrate, can't pay attention for long
0 1 2 9. Can't get his/her mind off certain thoughts; obsessions (describe): ______________________
0 1 2 10. Can't sit still, restless, or hyperactive
0 1 2 11. Clings to adults or too dependent
0 1 2 12. Complains of loneliness
0 1 2 13. Confused or seems to be in a fog
0 1 2 14. Cries a lot
0 1 2 15. Cruel to animals
0 1 2 16. Cruelty, bullying, or meanness to others
0 1 2 17. Daydreams or gets lost in his/her thoughts
0 1 2 18. Deliberately harms self or attempts suicide
0 1 2 19. Demands a lot of attention
0 1 2 20. Destroys his/her own things
0 1 2 21. Destroys things belonging to his/her family or others
0 1 2 22. Disobedient at home
0 1 2 23. Disobedient at school
0 1 2 24. Doesn't eat well
0 1 2 25. Doesn't get along with other kids
0 1 2 26. Doesn't seem to feel guilty after misbehaving
0 1 2 27. Easily jealous
0 1 2 28. Breaks rules at home, school, or elsewhere
0 1 2 29. Fears certain animals, situations, or places, other than school (describe): ______________________
0 1 2 30. Fears going to school
0 1 2 31. Fears he/she might think or do something bad
0 1 2 32. Feels he/she has to be perfect
0 1 2 33. Feels or complains that no one loves him/her
0 1 2 34. Feels others are out to get him/her
0 1 2 35. Feels worthless or inferior
0 1 2 36. Gets hurt a lot, accident-prone
0 1 2 37. Gets in many fights
0 1 2 38. Gets teased a lot
0 1 2 39. Hangs around with others who get in trouble
0 1 2 40. Hears sounds or voices that aren't there (describe): ______________________
0 1 2 41. Impulsive or acts without thinking
0 1 2 42. Would rather be alone than with others
0 1 2 43. Lying or cheating
0 1 2 44. Bites fingernails
0 1 2 45. Nervous, highstrung, or tense
0 1 2 46. Nervous movements or twitching (describe): ______________________
0 1 2 47. Nightmares
0 1 2 48. Not liked by other kids
0 1 2 49. Constipated, doesn't move bowels
0 1 2 50. Too fearful or anxious
0 1 2 51. Feels dizzy or lightheaded
0 1 2 52. Feels too guilty
0 1 2 53. Overeating
0 1 2 54. Overtired without good reason
0 1 2 55. Overweight

56. Physical problems ***without known medical cause:***

0 1 2 a. Aches or pains (***not*** stomach or headaches)
0 1 2 b. Headaches
0 1 2 c. Nausea, feels sick
0 1 2 d. Problems with eyes (***not*** if corrected by glasses) (describe): ______________________
0 1 2 e. Rashes or other skin problems
0 1 2 f. Stomachaches
0 1 2 g. Vomiting, throwing up
0 1 2 h. Other (describe): ______________________

Please print. Be sure to answer all items.

0 = Not True (as far as you know) **1 = Somewhat or Sometimes True** **2 = Very True or Often True**

[109]

0 1 2 57. Physically attacks people
0 1 2 58. Picks nose, skin, or other parts of body (describe): ______
0 1 2 59. Plays with own sex parts in public
0 1 2 60. Plays with own sex parts too much
0 1 2 61. Poor school work
0 1 2 62. Poorly coordinated or clumsy
0 1 2 63. Prefers being with older kids
0 1 2 64. Prefers being with younger kids
0 1 2 65. Refuses to talk
0 1 2 66. Repeats certain acts over and over; compulsions (describe): ______
0 1 2 67. Runs away from home
0 1 2 68. Screams a lot
0 1 2 69. Secretive, keeps things to self
0 1 2 70. Sees things that aren't there (describe): ______
0 1 2 71. Self-conscious or easily embarrassed
0 1 2 72. Sets fires
0 1 2 73. Sexual problems (describe): ______
0 1 2 74. Showing off or clowning
0 1 2 75. Too shy or timid
0 1 2 76. Sleeps less than most kids
0 1 2 77. Sleeps more than most kids during day and/or night (describe): ______
0 1 2 78. Inattentive or easily distracted
0 1 2 79. Speech problem (describe): ______
0 1 2 80. Stares blankly
0 1 2 81. Steals at home
0 1 2 82. Steals outside the home
0 1 2 83. Stores up too many things he/she doesn't need (describe): ______
0 1 2 84. Strange behavior (describe): ______
0 1 2 85. Strange ideas (describe): ______
0 1 2 86. Stubborn, sullen, or irritable
0 1 2 87. Sudden changes in mood or feelings
0 1 2 88. Sulks a lot
0 1 2 89. Suspicious
0 1 2 90. Swearing or obscene language
0 1 2 91. Talks about killing self
0 1 2 92. Talks or walks in sleep (describe): ______
0 1 2 93. Talks too much
0 1 2 94. Teases a lot
0 1 2 95. Temper tantrums or hot temper
0 1 2 96. Thinks about sex too much
0 1 2 97. Threatens people
0 1 2 98. Thumb-sucking
0 1 2 99. Smokes, chews, or sniffs tobacco
0 1 2 100. Trouble sleeping (describe): ______
0 1 2 101. Truancy, skips school
0 1 2 102. Underactive, slow moving, or lacks energy
0 1 2 103. Unhappy, sad, or depressed
0 1 2 104. Unusually loud
0 1 2 105. Uses drugs for nonmedical purposes (***don't*** include alcohol or tobacco) (describe): ______
0 1 2 106. Vandalism
0 1 2 107. Wets self during the day
0 1 2 108. Wets the bed
0 1 2 109. Whining
0 1 2 110. Wishes to be of opposite sex
0 1 2 111. Withdrawn, doesn't get involved with others
0 1 2 112. Worries
113. Please write in any problems your child has that were not listed above:
0 1 2 ______
0 1 2 ______
0 1 2 ______

Please be sure you answered all items.

SUBJECT ID #: _[110]______

SPINA BIFIDA SELF-MANAGEMENT PROFILE

Taking care of spina bifida means doing a lot of different things like doing clean intermittent catheterization, taking medications, handling infections, being on a bowel control program and cooperating with tests like x-rays and urologic (bladder) studies, It’s not easy doing all of these things exactly the way doctors and nurses might want. Very few kids with spina bifida and their families do everything exactly according to plan. Sometimes there are other things that grab your attention or you might just forget to take care of these things, even though you may have wanted to. Most kids with spina bifida, and their families, develop their own habits for taking care of it that are comfortable for them. What we’re trying to learn in this questionnaire is what you and your child usually do to take care of your child’s spina bifida. Your answers won’t be shared with anyone else, so you can feel comfortable writing exactly what you do not just what you think you’re supposed to do or what you think you should say. So, try to be completely honest about what you and your child have usually done in taking care of your child’s spina bifida in the past 6 months.

APPOINTMENT KEEPING

Taking care of spina bifida requires lots of clinic visits. Sometimes it’s hard to keep all of those appointments because you may be busy with lots of other important things. This part of the questionnaire is about what you and your child usually do about keeping medical appointments.

1. When your child has had medical appointments within the past 6 months, how often have you and your child come to that appointment? (please check one)

___ Arrived on time for every scheduled appointment
___ Came to every appointment but was a little late sometimes
___ Cancelled appointment more than 24 hours before the appointment and rescheduled another appointment
___ Arrived so late for an appointment that it had to be rescheduled
___ Forgot or otherwise did not come to an appointment

BOWEL CONTROL PROGRAM

[111]

Spina bifida makes it harder to have regular bowel movements and so your doctor may have given you a program to help you to develop consistent habits. This may include eating foods that contain plenty of fiber, staying away from some other foods, recording your bowel movements, and taking an enema or suppository if your bowel movements aren't frequent enough. This part of the questionnaire is about how carefully your child has done these things in the past 6 months.

2. In the past 6 months, how often has your child stayed within the diet recommendations that the doctor has given you? (please check one)

___ Always eats according to the recommendations (100%)
___ Usually eats according to the recommendations (80-100%)
___ Often eats according to the recommendations (50-80%)
___ Sometimes eats according to the recommendations (10-50%)
___ Rarely or never eats according to the recommendations (0-10%)

3. When your child has gotten constipated in the last 6 months, how often has your child taken a suppository, enema or stool-softening medication as prescribed by the doctor? (please check one)

___ No constipation in past 6 months
___ Always takes the prescribed enema, suppository or stool-softening medication as instructed (100% of the time)
___ Usually takes the prescribed enema, suppository or stool-softening medication as instructed (80-99% of the time)
___ Often takes the prescribed enema, suppository or stool softening medication as instructed (50-79% of the time)
___ Sometimes takes the prescribed enema, suppository or stool-softening medication as instructed (10-49% of the time)
___ Rarely or never takes the prescribed enema or suppository as instructed (Less than 10% of the time)

SKIN AND WOUND CARE

Most kids with spina bifida need to be careful about skin and wound care. Your care team[1 12] **may ask you and your child to check the skin on a daily basis for any sores or places where the skin is breaking down. It is important to recognize the signs of these kinds of wounds quickly, as they might develop into pressure sores that are difficult to heal. This question is about your usual habits in checking skin.**

4. In the past 6 months, how often did you and your child check your child's skin? (please check one)

___ Checks all over the body every day
___ Checks certain parts of body every day
___ Checks all over the body 2-3 times per week
___ Checks body once in a while
___ Rarely checks skin

EXERCISE

Your child's care team has probably explained the importance of getting some kind of exercise every day. Depending on how mobile your child is, this might include anything from walking, to moving around in a wheelchair, to doing arm pushups in a chair. Sometimes kids don't like to do this, or are busy with other things and would rather do other stuff. This question is about exercise.

5. In the past 6 months, how often does your child do the exercise that is asked of him or her? (please check one)

___ Does exercise every day on average
___ Does exercise every other day, on average
___ Does exercise one time, per week
___ Rarely exercises

MEDICATIONS

Treatment of spina bifida also often includes taking medicines for several different[113] purposes. Most kids and their families have at least some trouble taking all of these medicines in exactly the right amounts and at the scheduled times. This part of the questionnaire is about how regular your family is about giving medicines as the doctor has asked you and your child to do.

6. Many kids with spina bifida are expected to take antibiotics every day to prevent urinary tract infections, whether they are sick or not. How regular has your child been in taking this antibiotic in the past 6 months? (please check one)

___ Almost always takes the prescribed amount of antibiotic on time (Misses no more than two doses per month)
___ Usually takes the prescribed amount of antibiotic on time (Misses no more than 5 doses per month)
___ Often takes the prescribed amount of antibiotic on time (Misses no more than 10 doses per month)
___ Sometimes takes the prescribed amount of antibiotic on time (Misses no more than 20 doses per month)
___ Rarely or never takes the prescribed amount of antibiotic on time (Misses at least 20 doses per month)
___ Not prescribed antibiotics

7. Your child may also be asked to take Ditropan or a similar medicine to keep your bladder functioning well. In the past 6 months, how often has your child taken the correct dose of this medicine at the right time? (please check one)

___ Always takes the prescribed amount on time.
___ Usually (Over 80%) takes the prescribed amount on time
___ Often (50-80%) takes the prescribed amount on time
___ Sometimes (10-50%) takes the prescribed amount on time
___ Rarely or never (0-10%) takes the prescribed amount on time
___ Not prescribed this type of medicine

CLEAN INTERMITTENT CATHETERIZATION

Many kids with spina bifida must be catheterized several times daily, either by themselves[114] or their parents and these procedures must be followed very carefully. Lots of things can get in the way of doing this and, even when they try their best, many kids and parents still struggle with doing this exactly according to the plan. For example, it might be hard to follow every step of the procedure exactly as you were taught or to do it exactly on time. This part of the questionnaire will be asking about your family's habits about clean intermittent catheterization at home and away from home. Try to be as honest and accurate as you can about your catheterization habits in the past 6 months.

8. Many kids with spina bifida are asked to catheterize themselves, or to have their parents do this for them, several times daily. In the past 6 months, how often has this been done exactly according to schedule? (please check one)

___ Never or rarely misses doing catheterization as often as prescribed (Once a week or less)
___ Occasionally misses doing catheterization as often as prescribed (2-3 times a week)
___ Sometimes misses doing catheterization as often as prescribed (4-5 times a week)
___ Frequently misses doing catheterization as often as prescribed (Once a day)
___ Usually misses doing catheterization as often as prescribed (More than once a day)
___ Not asked to do clean intermittent catheterization

9. You and your child are asked to follow some careful steps whenever you complete catheterization. This includes five steps: 1.) Having all the supplies together, 2.) Washing your hands first, 3.) Correct positioning of the child, 4.) Inserting the catheter with slow steady pressure until urine begins to flow, and 5.) Washing the catheter in warm soapy water. In the past 6 months during catheterization, how many of these five steps do you or your child always do? (please check one)

___ Completes all five steps.
___ Completes four steps.
___ Completes three steps.
___ Completes two steps.
___ Completes 0-1 steps.

10. If you re-euse catheters, how often do sterilize the catheter by either washing it in antibacterial soap or boiling it in clean water for 10 minutes or more before you use it again? (please check one)

___ Does not re-use catheters.
___ Almost always sterilizes catheter between uses. (Misses no more than once per month)
___ Usually sterilizes catheter between uses. (Misses 2-5 times per month)
___ Often sterilizes catheter between uses. (Misses 6-10 times per month)
___ Sometimes sterilizes catheter between uses. (Misses 10-20 times per month)
___Infrequently or never sterilizes catheter between uses. (Misses more than 20 times per month)

DEALING WITH URINARY TRACT INFECTIONS

Most kids with spina bifida get urinary tract infections now and then. It is important to[116] **recognize the signs of these infections quickly, call in for treatment and take any medicines that are prescribed for this, but it isn't always easy to do these things. This part of the questionnaire is about your usual habits in recognizing urinary tract infections and the actions you take once you discover an infection.**

11. ln the past 6 months, what did you and your child usually do when you first thought that your child might have a urinary tract infection? (please check one)

___ No symptoms of urinary tract infection in the past 3 months
___ Call the clinic immediately to report the symptoms and get advice
___ Wait a few hours before calling to see if the symptoms went away
___ Wait until the next day before calling to see if the symptoms went away
___ Wait a few days before calling to see if the symptoms went away
___ Don't call at all

12.The last time your child had a urinary tract infection, how did your child do with taking the prescribed antibiotic medication <u>on time</u>? (please check one)

___ Always takes the prescribed amount of antibiotic on time (100%)
___ Usually takes the prescribed amount of antibiotic on time (80-100%)
___ Often takes the prescribed amount of antibiotic on time (50-80%)
___ Sometimes takes the prescribed amount of antibiotic on time (10-50%)
___ Rarely or never takes the prescribed amount of antibiotic on time (0-10%)

13. The last time your child had a urinary tract infection, how quickly did you fill the prescription for the antibiotic medication that the doctor prescribed for treating it? (please check one)

___ Within 6 hours after receiving the prescription
___ Between 6 and 12 hours after receiving the prescription
___ Between 12 and 24 hours after receiving the prescription
___ More than 24 hours after receiving the prescription
___ Did not fill the prescription

14.The last time your child had a urinary tract infection, <u>how much</u> of the prescribed antibiotic medication did your child actually take? (please check one)

___ Took every scheduled dose until the medicine was gone
___ Took at least 80% of scheduled doses of the medicine
___ Took 50-80% of the scheduled doses of the medicine
___ Took 10-5% of the scheduled doses of the medicine
___ Took less than 10% of the scheduled doses of the medicine
___ Did not fill the prescription

The SNAP-IV Teacher and Parent Rating Scale

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For each item, check the column that best describes this child:

	Not At All	Just A Little	Quite A Bit	Very Much
1. Often fails to give close attention to details or makes careless mistakes in schoolwork or tasks	______	______	______	______
2. Often has difficulty sustaining attention in tasks or play activities	______	______	______	______
3. Often does not seem to listen when spoken to directly	______	______	______	______
4. Often does not follow through on instructions and fails to finish schoolwork, chores, or duties	______	______	______	______
5. Often has difficulty organizing tasks and activities	______	______	______	______
6. Often avoids, dislikes, or reluctantly engages in tasks requiring sustained mental effort	______	______	______	______
7. Often loses things necessary for activities (e.g., toys, school assignments, pencils, or books)	______	______	______	______
8. Often is distracted by extraneous stimuli	______	______	______	______
9. Often is forgetful in daily activities	______	______	______	______
10. Often fidgets with hands or feet or squirms in seat	______	______	______	______
11. Often leaves seat in classroom or in other situations in which remaining seated is expected	______	______	______	______
12. Often runs about or climbs excessively in situations in which it is inappropriate	______	______	______	______
13. Often has difficulty playing or engaging in leisure activities quietly	______	______	______	______
14. Often is “on the go” or often acts as if “driven by a motor”	______	______	______	______
15. Often talks excessively	______	______	______	______
16. Often blurts out answers before questions have been completed	______	______	______	______
17. Often has difficulty awaiting turn	______	______	______	______
18. Often interrupts or intrudes on others (e.g., butts into conversations/games)	______	______	______	______

BRIEF
Parent Form

Instructions:

On the following pages is a list of statements that describe children. We would like to know if your child has had problems with these behaviors over the past 6 months. Please answer all the items the best that you can. Please DO NOT SKIP ANY ITEMS. Think about your child as you reach each statement and circle your response:

N	if the behavior is	**Never** a problem
S	if the behavior is	**Sometimes** a problem
O	if the behavior is	**Often** a problem

N=Never **S=Sometimes** **O=Often**

1. Overreacts to small problems	N	S	O
2. When given three things to do, remembers only the first or last	N	S	O
3. Is not a self-starter	N	S	O
4. Leaves playroom a mess	N	S	O
5. Resists or has trouble accepting a different way to solve a problem with schoolwork, friends, chores, etc.	N	S	O
6. Becomes upset with new situations	N	S	O
7. Has explosive, angry outbursts	N	S	O
8. Tries the same approach to a problem over and over even when it does not work.	N	S	O
9. Has a short attention span	N	S	O
10. Needs to be told to begin a task even when willing	N	S	O
11. Does not bring home homework, assignment sheets, materials, etc.	N	S	O
12. Acts upset by a change in plans	N	S	O
13. Is disturbed by change of teacher or class	N	S	O
14. Does not check work for mistakes	N	S	O
15. Has good ideas but cannot get them on paper	N	S	O
16. Has trouble coming up with ideas for what to do in play or free time	N	S	O
17. Has trouble concentrating on chores, schoolwork, etc.	N	S	O
18. Does not connect doing tonight’s homework with grades	N	S	O

N=Never S=Sometimes O=Often

19. Is easily distracted by noises, activity, sights, etc.	N	S	O
20. Becomes tearful easily	N	S	O
21. Makes careless errors	N	S	O
22. Forgets to hand in homework, even when completed	N	S	O
23. Resists change of routine, foods, places, etc.	N	S	O
24. Has trouble with chores or tasks that have more than one step	N	S	O
25. Has outbursts for little reason	N	S	O
26. Mood changes frequently	N	S	O
27. Needs help from an adult to stay on task	N	S	O
28. Gets caught up in details and misses the big picture	N	S	O
29. Keeps room messy	N	S	O
30. Has trouble getting used to new situations (classics, groups, friends)	N	S	O
31. Has poor handwriting	N	S	O
32. Forgets what he/she was doing	N	S	O
33. When sent to get something, forgets what he/she is supposed to get	N	S	O
34. Is unaware of how his/her behavior affects or bothers others	N	S	O
35. Has good ideas but does not get job done (lacks follow-through)	N	S	O
36. Becomes overwhelmed by large assignments	N	S	O
37. Has trouble finishing tasks (chores, homework)	N	S	O
38. Acts wilder or sillier than others in groups (birthday parties, recess)	N	S	O
39. Thinks too much about the same topic	N	S	O
40. Underestimates time needed to finish tasks	N	S	O
41. Interrupts others	N	S	O
42. Does not notice when his/her behavior causes negative reactions	N	S	O
43. Gets out of seat at the wrong times	N	S	O
44. Gets out of control more than his/her friends	N	S	O
45. Reacts more strongly than other children	N	S	O
46. Starts assignments or chores at the last minute	N	S	O
47. Has trouble getting started on homework or chores	N	S	O
48. Has trouble organizing activities with friends	N	S	O
49. Blurts things out	N	S	O
50. Mood is easily influenced by the situation	N	S	O
51. Does not plan ahead for school assignments	N	S	O
52. Has poor understanding of own strengths and weaknesses	N	S	O
53. Written work is poorly organized	N	S	O
54. Acts too wild or “out of control”	N	S	O
55. Has trouble putting the brakes on his/her actions	N	S	O
56. Gets in trouble if not supervised by an adult	N	S	O
57. Has trouble remembering things, even for a few minutes	N	S	O
58. Has trouble carrying out the actions needed to reach goals (saving money for special item, studying to get a good grade)	N	S	O
59. Becomes too silly	N	S	O
60. Work is sloppy	N	S	O

N=Never S=Sometimes O=Often

61. Does not take initiative	N	S	O
62. Angry or tearful outbursts are intense but end suddenly	N	S	O
63. Does not realize that certain actions bother others	N	S	O
64. Small events trigger big reactions	N	S	O
65. Talks at the wrong time	N	S	O
66. Complains there is nothing to do	N	S	O
67. Cannot find things in room or school desk	N	S	O
68. Leaves a trail of belongings wherever he/she goes	N	S	O
69. Leaves messes that others have to clean up	N	S	O
70. Becomes upset too easily	N	S	O
71. Lies around the house a lot (“couch potato”)	N	S	O
72. Has a messy closet	N	S	O
73. Has trouble waiting for turn	N	S	O
74. Loses lunch box, lunch money, permission slips, homework, etc.	N	S	O
75. Cannot find clothes, glasses, shoes, toys, books, pencils, etc.	N	S	O
76. Tests poorly even when he/she knows the correct answers	N	S	O
77. Does not finish long-term projects	N	S	O
78. Has to be closely supervised	N	S	O
79. Does not think before doing	N	S	O
80. Has trouble moving from one activity to another	N	S	O
81. Is fidgety	N	S	O
82. Is impulsive	N	S	O
83. Cannot stay on the same topic when talking	N	S	O
84. Says the same things over and over	N	S	O
85. Has trouble getting through morning routine in getting ready for school	N	S	O

[120]

RSCAB ID# _________

For the following, first decide what is true for your child—the one described on the left or right— and then indicate whether this is just sort of true or really true for your child. Thus, for each item, check **only one** of four spaces.

Sample Sentence

	Really True For My Child	Sort Of True For My Child				Sort Of True For My Child	Really True For My Child
(a)	______	___X__	My child would rather play outdoors in his/her spare time	OR	My child would rather watch T.V.	______	______

1.	______	______	My child is really good at his/her school work	OR	My child can't do the work assigned	______	______
2.	______	______	My child finds it hard to make friends	OR	For my child it's pretty easy	______	______
3.	______	______	My child does really well at all kinds of sports	OR	My child isn't very good when it comes to sports	______	______
4.	______	______	My child is good-looking	OR	My child is not very good-looking	______	______
5.	______	______	My child is usually well-behaved	OR	My child is often not well-behaved	______	______
6.	______	______	My child often forgets what he/she learns	OR	My child can remember things easily	______	______
7.	______	______	My child has a lot of friends	OR	My child doesn't have many friends	______	______

	Really True For My Child	Sort Of True For My Child				Sort of True For My Child	Really True For My Child
8.	______	______	My child is better than others his/her age at sports	OR	My child can't play very well	______	______
9.	______	______	My child has a nice physical appearance	OR	My child doesn't have a nice physical appearance	______	______
10.	______	______	My child usually acts appropriately	OR	My child would be better if he/she acted differently	______	______
11.	______	______	My child has trouble figuring out answers in school	OR	My child almost always can figure out the answers	______	______
12.	______	______	My child is popular with others his/her age	OR	My child is not very popular	______	______
13.	______	______	My child doesn't do well at new outdoor games	OR	My child is good at new games right away	______	______
14.	______	______	My child isn't very attractive	OR	My child is pretty attractive	______	______
15.	______	______	My child often gets in trouble because of things he/she does	OR	My child usually doesn't do things that get him/her in trouble	______	______

In the past **ONE month**, how much of a **problem** has your child had with . . .

Physical Functioning (***PROBLEMS WITH . . .***)	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. Walking more than one block	0	1	2	3	4
2. Running	0	1	2	3	4
3. Participating in sports activity or exercise	0	1	2	3	4
4. Lifting something heavy	0	1	2	3	4
5. Taking a bath or shower by him or herself	0	1	2	3	4
6. Doing chores around the house	0	1	2	3	4
7. Having hurts or aches	0	1	2	3	4
8. Low energy level	0	1	2	3	4

Emotional Functioning (***PROBLEMS WITH . . .***)	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. Feeling afraid or scared	0	1	2	3	4
2. Feeling sad or blue	0	1	2	3	4
3. Feeling angry	0	1	2	3	4
4. Trouble sleeping	0	1	2	3	4
5. Worrying about what will happen to him or her	0	1	2	3	4

Social Functioning (***problems with . . .***)	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. Getting along with other children	0	1	2	3	4
2. Other kids not wanting to be his or her friend	0	1	2	3	4
3. Getting teased by other children	0	1	2	3	4
4. Not able to do things that other children his or her age can do	0	1	2	3	4
5. Keeping up when playing with other children	0	1	2	3	4

School Functioning (***problems with . . .***)	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. Paying attention in class	0	1	2	3	4
2. Forgetting things	0	1	2	3	4
3. Keeping up with schoolwork	0	1	2	3	4
4. Missing school because of not feeling well	0	1	2	3	4
5. Missing school to go to the doctor or hospital	0	1	2	3	4

FSS-MM

The following is a list of things that may be stressful when raising a child with spina bifida. We would like you to think of stress as meaning something that taxes your resources, or as something that is more than you can handle comfortably. Please rate the stressfulness of each item on the scale below:

1 = not at all stressful
2 = a bit stressful
3 = fairly stressful
4 = quite stressful
5 = extremely stressful

	Not at all stressful	A bit stressful	Fairly stressful	Quite stressful	Extremely stressful
1. Outings in the community	1	2	3	4	5
2. Relationships with our friends or extended family.	1	2	3	4	5
3. Discipline.	1	2	3	4	5
4. My marital/intimate relationship.	1	2	3	4	5
5. Mealtimes and bedtimes.	1	2	3	4	5
6. Educational concerns.	1	2	3	4	5
7. Safety.	1	2	3	4	5
8. Communication with my child.	1	2	3	4	5
9. My child's relations with other children.	1	2	3	4	5

	Not at all stressful	A bit stressful	Fairly stressful	Quite stressful	Extremely stressful
10. My child's behavior problems.	1	2	3	4	5
11. My child's emotional problems.	1	2	3	4	5
12. My child's relationships with his/her brother(s) and sister(s).	1	2	3	4	5
13. Financial responsibilities.	1	2	3	4	5
14. Medical care/appointments.	1	2	3	4	5
15. Catheterization.	1	2	3	4	5
16. Medications.	1	2	3	4	5
17. Bowel program.	1	2	3	4	5
18. Food/diet.	1	2	3	4	5
19. Braces/wheelchair/ambulation.	1	2	3	4	5

SPINA BIFIDA PAIN QUESTIONNAIRE
Child/ Adolescent version

1) How severe is your spina bifida **at the present time**? (*Put a mark anywhere along the line to show how severe you believe your spina bifida is.)*

Not severe at all Extremely severe

2) In the **last three months**, how often have you had aches, discomfort, or pain due to spina bifida? (*Please circle the best response.*)

- ☐ (0) Less than once per month
- ☐ (1) 1 to 3 times per month
- ☐ (2) 1 time per week
- ☐ (3) 2 to 3 times per week
- ☐ (4) 3 to 5 times per week
- ☐ (5) Daily
- ☐ (6) Not applicable

3) How much does your discomfort/ pain **usually** hurt? *(Put a mark anywhere on the line below.)*

No discomfort/ pain Worst discomfort/ pain ever

4) How long does your discomfort/ pain **usually** last?

- ☐ (0) Less than 1 hour
- ☐ (1) A few hours
- ☐ (2) Half of the day
- ☐ (3) All day
- ☐ (4) Not applicable

5) In the **past three months,** how much has pain from spina bifida **bothered or upset** you?

☐ (0) Not at all
☐ (1) A little
☐ (2) Between a little and a lot
☐ (3) A lot
☐ (4) Very much
☐ (5) Not applicable

6) How do you cope with your limitations due to spina bifida **at the present time**? (*Put a mark anywhere on the line below.)*

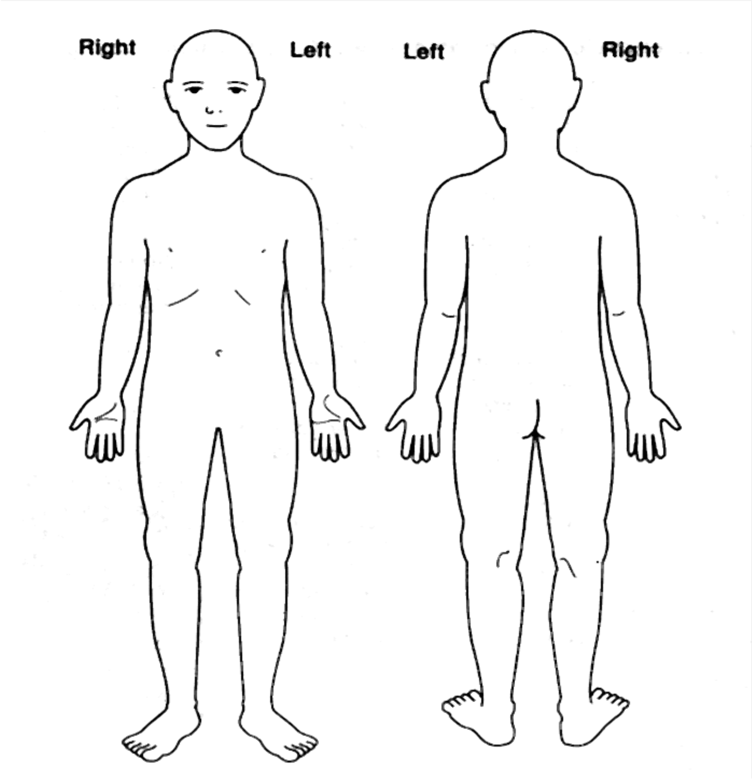
Give in to limitations (restrict all activities)	Try to overcome limitations (do not restrict activities)

7) Are there things that help you feel better when you have discomfort/ pain due to spina bifida?

☐ (0) Never
☐ (1) Rarely
☐ (2) Sometimes
☐ (3) Often
☐ (4) Usually
☐ (5) Not applicable

8) Please list what helps you feel better:

9) Where is your discomfort/ pain located? *(Please mark area(s) on figure.)*



☐ (1) Not applicable

10) What words best describe your discomfort/ pain? *(Check **all** that apply.)*

☐ (1) Sharp
☐ (2) Aching
☐ (3) Stinging
☐ (4) Hammering
☐ (5) Dull

☐ (6) Throbbing
☐ (7) Burning
☐ (8) Pounding
☐ (9) Cutting
☐ (10) Other______________

☐ (11) Not applicable

11) Is there a time of day or night when the discomfort/ pain hurts the most?

- ☐ (0) No
- ☐ Yes:
- ☐ (1) Waking up
- ☐ (2) Morning
- ☐ (3) Afternoon
- ☐ (4) Evening
- ☐ (5) Bedtime
- ☐ (6) Mealtime
- ☐ (7) Not applicable

12) Do you **usually** have any warning that you are going to have discomfort/ pain?

- ☐ (0) No
- ☐ (1) Yes *(specify______________________________)*
- ☐ (2) Not applicable

13) Do you **usually** wake up at night (or during a nap) due to discomfort/ pain?

- ☐ (0) No
- ☐ (1) Yes
- ☐ (2) Not applicable

14) How frequently do you wake up due to discomfort/ pain?

- ☐ (0) 0 times, I do not wake up due to discomfort/ pain
- ☐ (1) 1-2 times/ night
- ☐ (2) 3-4 times/ night
- ☐ (3) More than 4 times/ night
- ☐ (4) Not applicable

CDI

Kids sometimes have different feelings and ideas.

This form lists the feelings and ideas in groups. From each group of three sentences, pick the ***one*** sentence that describes you ***best*** for the past ***two*** weeks**.** After you pick a sentence from the first group, go on to the next group.

There is no right or wrong answer. Just pick the sentence that best describes the way you have been recently. Put a mark like this ☑ next to your answer. Put the mark in the box next to the sentence that you pick.

Here is an example of how this form works. Try it. Put a mark next to the sentence that describes you ***best***.

Example:

☐ I read books all the time.
☐ I never read books.
☐ I read books once in awhile.

Remember, pick out the sentence that describes you best in the PAST TWO WEEKS.

Remember describe how you have been in the past two weeks…

Item 1
- ☐ I am sad once in a while.
- ☐ I am sad many times.
- ☐ I am sad all the time.

Item 2
- ☐ Nothing will ever work out for me.
- ☐ I am not sure if things will work out for me.
- ☐ Things will work out for me O.K.

Item 3
- ☐ I do most things O.K.
- ☐ I do many things wrong.
- ☐ I do everything wrong.

Item 4
- ☐ I have fun in many things.
- ☐ I have fun in some things.
- ☐ Nothing is fun at all.

Item 5
- ☐ I am bad all the time.
- ☐ I am bad many times.
- ☐ I am bad once in a while.

Item 6
- ☐ I think about bad things happening to me once in a while.
- ☐ I worry that bad things will happen to me.
- ☐ I am sure that terrible things will happen to me.

Item 7
- ☐ I hate myself.
- ☐ I do not like myself.
- ☐ I like myself.

Item 8
- ☐ All bad things are my fault.
- ☐ Many bad things are my fault
- ☐ Bad things are not usually my fault.

Item 9
- ☐ I do not think about killing myself.
- ☐ I think about killing myself, but I would not do it.
- ☐ I want to kill myself.

Item 10
- ☐ I feel like crying everyday.
- ☐ I feel like crying most days.
- ☐ I feel like crying once in a while.

Item 11
- ☐ Things bother me all the time.
- ☐ Things bother me many times.
- ☐ Things bother me once in a while.

Item 12
- ☐ I like being with people.
- ☐ I do not like being with people many times.
- ☐ I do not want to be with people at all.

Item 13
- ☐ I cannot make up my mind about things.
- ☐ It is hard to make up my mind about things.
- ☐ I make up my mind about things easily.

Item 14
- ☐ I look O.K.
- ☐ There are some bad things about my looks.
- ☐ I look ugly.

Remember, describe how you have been in the past two weeks… [131]

Item 15
- ☐ I have to push myself all the time to do my schoolwork.
- ☐ I have to push myself many times to do my schoolwork.
- ☐ Doing schoolwork is not a big problem.

Item 16
- ☐ I have trouble sleeping every night.
- ☐ I have trouble sleeping many nights.
- ☐ I sleep pretty well.

Item 17
- ☐ I am tired once in a while.
- ☐ I am tired many days.
- ☐ I am tired all the time.

Item 18
- ☐ Most days I do not feel like eating.
- ☐ Many days I do not feel like eating.
- ☐ I eat pretty well.

Item 19
- ☐ I do not worry about aches and pains.
- ☐ I worry about aches and pains many times.
- ☐ I worry about aches and pains all the time.

Item20
- ☐ I do not feel alone.
- ☐ I feel alone many times.
- ☐ I feel alone all the time.

Item 21
- ☐ I never have fun at school.
- ☐ I have fun at school only once in a while.
- ☐ I have fun at school many times.

Item 22
- ☐ I have plenty of friends.
- ☐ I have some friends but I wish I had more.
- ☐ I do not have any friends.

Item 23
- ☐ My schoolwork is alright.
- ☐ My schoolwork is not as good as before.
- ☐ I do very badly in subjects I used to be good in.

Item 24
- ☐ I can never be as good as other kids.
- ☐ I can be as good as other kids if I want to.
- ☐ I am just as good as other kids.

Item 25
- ☐ Nobody really loves me.
- ☐ I am not sure if anybody loves me.
- ☐ I am sure that somebody loves me.

Item 26
- ☐ I usually do what I am told.
- ☐ I do not do what I am told most times.
- ☐ I never do what I am told.

Item 27
- ☐ I get along with people.
- ☐ I get into fights many times.
- ☐ I get into fights all the time.

CSPI

Read each question carefully and PRETEND what it says is happening to you. Then CIRCLE how easy it would be for you to do the things in each question. Some kids your age think these things are hard to do, other kids your age think these things are easy to do. We want you to circle the answer that is really true for you.

Remember, this is not a test and there are no right or wrong answers. Be sure to CIRCLE the answer that is really true for you. Here is an example for you to try:

A. A kid doesn't want you to play. Telling the kid to let you play is ___________ for you.

very hard   hard   easy   very easy

1. Some kids want to play a game. Asking them if you can play is __________ for you.
   very hard hard easy very easy

2. Some kids are arguing about how to play a game. Telling them the rules is _________ for you.
   very hard hard easy very easy

3. Some kids are teasing your friend. Telling them to stop is __________ for you.
   very hard hard easy very easy

4. You want to start a game. Asking other kids to play the game is _________ for you.
   very hard hard easy very easy

5. A kid tries to take your turn during a game. Telling the kid it's your turn is _________ for you.
   very hard hard easy very easy

6. Some kids are going to lunch. Asking if you can sit with them is _________ for you.
   very hard hard easy very easy

7. A kid cuts in front of you in line. Telling the kid not to cut is _________ for you.
   very hard hard easy very easy

8. A kid wants to do something that will get you into trouble. Asking the kid to do something else is _________ for you.
   very hard hard easy very easy

9. Some kids are making fun of someone in your classroom. Telling them to stop is _________ for you.
   very hard hard easy very easy

10. Some kids need more people to be on their teams. Asking if you can be on a team is _________ for you.
    very hard hard easy very easy

11. You have to carry some things home after school. Asking another kid to help you is _________ for you.

very hard hard easy very easy

12. A kid always wants to be first when you play a game. Telling the kid you are going first is _________ for you.

very hard hard easy very easy

13. Your class is going on a trip and everyone needs a partner. Asking someone to be your partner is _________ for you.

very hard hard easy very easy

14. A kid does not like your friend. Asking the kid to be nice to your friend is _________ for you.

very hard hard easy very easy

15. You are working on a project. Asking another kid to help is _________ for you.

very hard hard easy very easy

16. Some kids are deciding what to do after school. Telling them what you want to do is __________ for you.

very hard hard easy very easy

17. Some kids are planning a party. Asking them to invite your friend is _________ for you.

very hard hard easy very easy

18. A kid is yelling at you. Telling the kid to stop is _________ for you.

very hard hard easy very easy

WIAL-C

For the following, first decide what is true for you—the one described on the left or right— and then indicate whether this is just sort of true or really true for you. Thus, for each item, check **only one** of four spaces.

Sample Sentence

	Really True For Me	Sort Of True For Me				Sort Of True For Me	Really True For Me
(a)	_____	_____	Some kids would rather play outdoors in their spare time	BUT	Other kids would rather watch T.V.	__X__	_____
1.	_____	_____	Some kids find it *hard* to make friends	BUT	Other kids find it's pretty *easy* to make friends	_____	_____
2.	_____	_____	Some kids have *a lot* of friends	BUT	Other kids *don't* have very many friends	_____	_____
3.	_____	_____	Some kids would like to have a lot more friends	BUT	Other kids have as many friends as they want	_____	_____
4.	_____	_____	Some kids are always doing things with *a lot* of kids	BUT	Other kids usually do things by *themselves*	_____	_____
5.	_____	_____	Some kids wish that more people their age liked them	BUT	Other kids feel that most people their age *do* like them	_____	_____
6.	_____	_____	Some kids are *popular* with others their age	BUT	Other kids are *not* very popular	_____	_____

FRIENDSHIP ACTIVITY QUESTIONNAIRE

Put the name of your very best friend here: ___________________________________

We want to ask you some questions just about you and the person you think of as your best friend so we can know what your best friend is like. We have some sentences that we would like you to read. Please tell us whether this sentence describes your friendship or not. Some of the sentences might be really true for your friendship while other sentences might not be very true for your friendship. We simply want you to read the sentence and tell us how true the sentence is for your friendship. Remember, there are no right or wrong ways to answer these questions, and you can use any of the numbers on the scale.

After each sentence there is a scale that goes from 1 to 5

"1" means the sentence is probably not true for your friendship
"2" means that it might be true
"3" means that it is usually true
"4" means that it is very true
"5" means that it is <u>really</u> true for your friendship

Circle the number on the scale that is best for you. Be sure to read carefully and answer as honestly as possible.

<u>Example</u>

X1. My friend and I play games and other activities with each other	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5

1. My friend and I spend a lot of our free time together.	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
2. My friend gives me advice when I need it	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
3. My friend and I do things together	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
4. My friend and I help each other	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
5. Even if my friend and I have an argument, we would still be able to be friends with each other	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5

BE SURE TO THINK ABOUT YOUR BEST FRIEND WHEN YOU ANSWER THESE QUESTIONS

6. My friend and I play together at recess	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
7. If other kids were bothering me, my friend would help me	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
8. Our friendship is just as important to me as it is to my friend	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
9. I can trust and rely upon my friend	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
10. My friend helps me when I am having trouble with something	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
11. If my friend had to move away, I would miss him/her	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
12. If I can't figure out how to do something, my friend shows me how	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
13. Sometimes it seems that I care more about our friendship than my friend does	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
14. When I do a good job at something, my friend is happy for me	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
15. There is nothing that would stop my friend and I from being friends	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
16. Sometimes my friend does things for me or makes me feel special	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
17. When my friend and I have an argument, he/she can hurt my feelings	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
18. When I have not been with my friend for a while, I really miss being with him/her	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
19. If somebody tried to push me around, my friend would help me	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
20. I can get into fights with my friend	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
21. My friend would stick up for me if another kid was causing me trouble	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5

BE SURE TO THINK ABOUT YOUR BEST FRIEND WHEN YOU ANSWER THESE QUESTIONS

22. When we have free time at school, such as at lunchtime or recess, my friend and I usually do something together or spend time with each other	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
23. If I have a problem at school or at home, I can talk to my friend about it	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
24. My friend can bug me or annoy me even though I ask him/her not to	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
25. If I forgot my lunch or needed a little money, my friend would loan it to me	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
26. I think of things for us to do more often than my friend does	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
27. If I said I was sorry after I had a fight with my friend, he/she would still stay mad at me	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
28. My friend helps me with tasks that are hard or that need two people	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
29. My friend and I go to each other’s houses after school and on weekends	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
30. Sometimes my friend and I just sit around and talk about things like school, sports, and other things we like	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
31. If I have questions about something, my friend would help me get some answers	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
32. Even if other people stopped liking me, my friend would still be my friend	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
33. I know that I am important to my friend	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
34. My friend would help me if I needed it	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
35. Being friends together is more important to me than it is to my friend	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
36. If there is something bothering me I can tell my friend about it, even if it is something I can not tell to other people	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
37. Things are usually pretty even in my friendship	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5

BE SURE TO THINK ABOUT YOUR BEST FRIEND WHEN YOU ANSWER THESE QUESTIONS

38. My friend puts our friendship ahead of other things	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
39. When I have to do something that is hard, I can count on my friend for help.	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
40. If my friend or I do something that bothers the other one of us, we can make up easily	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
41. My friend and I can argue a lot	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
42. My friend and I disagree about many things	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
43. If my friend and I have a fight or argument, we can say "I'm sorry" and everything will be alright	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
44. I feel happy when I am with my friend	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
45. My friend likes me as much as I like him/her	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5
46. I think about my friend even when my friend is not around	NOT TRUE 1	MIGHT BE TRUE 2	USUALLY TRUE 3	VERY TRUE 4	REALLY TRUE 5

EMOTIONAL SUPPORT QUESTIONNAIRE

We are interested in understanding how students get help with their personal problems, worries, or concerns. This questionnaire asks about people in your life who may or may not be sources of help. [140]

Please list below the three people you consider most important in your life who fit in each category provided. Please write down their relationship to you and their first initial; for example: stepmother B; teacher R; friend D, etc. Then please answer all the questions for each person listed by circling the appropriate responses. An example is provided.

1. Relationship and Initial (ex: Stepmother S; Coach T; Aunt M)	**2. Sex**	**3. How much do you talk to them about personal concerns?** **1=hardly at all** **2=a little** **3=pretty much** **4=very much**	**4. How close do you feel to them?** **1=hardly at all** **2=a little** **3=pretty much** **4=very much**	**5. How much do they talk to you about their concerns?** **1=hardly at all** **2=a little** **3=pretty much** **4=very much**	**6. How satisfied are you with the help and support they give you?** **1=hardly at all** **2=a little** **3=pretty much** **4=very much**	**7. How much do you and this person get upset with or mad at each other?** **1=hardly at all** **2=a little** **3=pretty much** **4=very much**	**8. How much do you play around and have fun with this person?** **1=hardly at all** **2=a little** **3=pretty much** **4=very much**	**9. How sure are you that this relationship will last no matter what?** **1=hardly at all** **2=a little** **3=pretty much** **4=very much**
Example: Mother G	**M F**	**1 2 3 4**	**1 2 3 4**	**1 2 3 4**	**1 2 3 4**	**1 2 3 4**	**1 2 3 4**	**1 2 3 4**
A. Family Members **1.** **2.** **3.**	**M F** **M F** **M F**	**1 2 3 4** **1 2 3 4** **1 2 3 4**	**1 2 3 4** **1 2 3 4** **1 2 3 4**	**1 2 3 4** **1 2 3 4** **1 2 3 4**	**1 2 3 4** **1 2 3 4** **1 2 3 4**	**1 2 3 4** **1 2 3 4** **1 2 3 4**	**1 2 3 4** **1 2 3 4** **1 2 3 4**	**1 2 3 4** **1 2 3 4** **1 2 3 4**
B. Non-Family Adults (ex: Coach, Teacher, Counselor) **1.** **2.** **3.**	**M F** **M F** **M F**	**1 2 3 4** **1 2 3 4** **1 2 3 4**	**1 2 3 4** **1 2 3 4** **1 2 3 4**	**1 2 3 4** **1 2 3 4** **1 2 3 4**	**1 2 3 4** **1 2 3 4** **1 2 3 4**	**1 2 3 4** **1 2 3 4** **1 2 3 4**	**1 2 3 4** **1 2 3 4** **1 2 3 4**	**1 2 3 4** **1 2 3 4** **1 2 3 4**
C. Friends **1.** **2.** **3.**	**M F** **M F** **M F**	**1 2 3 4** **1 2 3 4** **1 2 3 4**	**1 2 3 4** **1 2 3 4** **1 2 3 4**	**1 2 3 4** **1 2 3 4** **1 2 3 4**	**1 2 3 4** **1 2 3 4** **1 2 3 4**	**1 2 3 4** **1 2 3 4** **1 2 3 4**	**1 2 3 4** **1 2 3 4** **1 2 3 4**	**1 2 3 4** **1 2 3 4** **1 2 3 4**

In the past **ONE month**, how much of a **problem** has this been for you . . .

About My Health and Activities (*PROBLEMS WITH . . .*)	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. It is hard for me to walk more than one block	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do sports activity or exercise	0	1	2	3	4
4. It is hard for me to lift something heavy	0	1	2	3	4
5. It is hard for me to take a bath or shower by myself	0	1	2	3	4
6. It is hard for me to do chores around the house	0	1	2	3	4
7. I hurt or ache	0	1	2	3	4
8. I have low energy	0	1	2	3	4

About My Feelings (*PROBLEMS WITH* **. . .**)	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad or blue	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4

How I Get Along with Others (*problems with* **. . .**)	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. I have trouble getting along with other kids	0	1	2	3	4
2. Other kids do not want to be my friend	0	1	2	3	4
3. Other kids tease me	0	1	2	3	4
4. I cannot do things that other kids my age can do	0	1	2	3	4
5. It is hard to keep up when I play with other kids	0	1	2	3	4

About School (*problems with* **. . .)**	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. It is hard to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my schoolwork	0	1	2	3	4
4. I miss school because of not feeling well	0	1	2	3	4
5. I miss school to go to the doctor or hospital	0	1	2	3	4

TEACHER'S REPORT FORM FOR AGES 6-18

For office use only
ID #

Your answers will be used to compare the pupil with other pupils whose teachers have completed similar forms. The information from this form will also be used for comparison with other information about this pupil. Please answer as well as you can, even if you lack full information. Scores on individual items will be combined to identify general patterns of behavior. Feel free to print additional comments beside each item and in the spaces provided on page 2. ***Please print, and answer all items.***

PUPIL'S FULL NAME First Middle Last

PUPIL'S GENDER ☐ Boy ☐ Girl

PUPIL'S AGE

PUPIL'S ETHNIC GROUP OR RACE

TODAY'S DATE Mo.______ Date______ Yr.______

PUPIL'S BIRTHDATE (if known) Mo.______ Date______ Yr.______

GRADE IN SCHOOL ________

NAME AND ADDRESS OF SCHOOL

PARENTS' USUAL TYPE OF WORK, even if not working now *(Please be specific — for example, auto mechanic, high school teacher, homemaker, laborer, lathe operator, shoe salesman, army sergeant.)*

FATHER'S TYPE OF WORK ______________________

MOTHER'S TYPE OF WORK ______________________

THIS FORM FILLED OUT BY: (*print your full name*)

Your gender: ☐ Male ☐ Female

Your role at the school:

☐ Classroom Teacher ☐ Counselor

☐ Special Educator ☐ Administrator

☐ Teacher's Aide ☐ Other (specify):

I. For how many months have you known this pupil? __________ **months**

II. How well do you know him/her? 1. ☐ Not Well 2. ☐ Moderately Well 3. ☐ Very Well

III. How much time does he/she spend in your class or service per week?

IV. What kind of class or service is it? (Please be specific, e.g., regular 5th grade, 7th grade math, learning disability, counseling, etc.)

V. Has he/she ever been referred for special class placement, services, or tutoring?

☐ Don't Know 0. ☐ No 1. ☐ Yes — what kind and when?

VI. Has he/she repeated any grades? ☐ Don't Know 0. ☐ No 1. ☐ Yes — grades and reasons:

VII. Current academic performance — list academic subjects and check box that indicates pupil's performance for each subject:

Academic subject	1. Far below grade	2. Somewhat below grade	3. At grade level	4. Somewhat above grade	5. Far above grade
1. ____________	☐	☐	☐	☐	☐
2. ____________	☐	☐	☐	☐	☐
3. ____________	☐	☐	☐	☐	☐
4. ____________	☐	☐	☐	☐	☐
5. ____________	☐	☐	☐	☐	☐
6. ____________	☐	☐	☐	☐	☐

Be sure you answered all items. Then see other side.

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www.ASEBA.org

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Please print. Be sure to answer all items.

VIII. Compared to typical pupils of the same age:	1. Much less	2. Somewhat less	3. Slightly less	4. About average	5. Slightly more	6. Somewhat more	7. Much more
1. How hard is he/she working?	☐	☐	☐	☐	☐	☐	☐
2. How appropriately is he/she behaving?	☐	☐	☐	☐	☐	☐	☐
3. How much is he/she learning?	☐	☐	☐	☐	☐	☐	☐
4. How happy is he/she?	☐	☐	☐	☐	☐	☐	☐

IX. Most recent achievement test scores (optional):

Name of test	Subject	Date	Percentile or grade level obtained

X. IQ, readiness, or aptitude tests (optional):

Name of test	Date	IQ or equivalent scores

Does this pupil have any illness or disability (either physical or mental)? ☐ No ☐ Yes— please describe:

What concerns you most about this pupil?

Please describe the best things about this pupil:

Please feel free to write any comments about this pupil's work, behavior, or potential, using extra pages if necessary.

Please print. Be sure to answer all items.

Below is a list of items that describe pupils. For each item that describes the pupil ***now or within the past 2 months,*** please circle the *2* if the item is ***very true or often true*** of the pupil. Circle the *1* if the item is ***somewhat or sometimes true*** of the pupil. If the item is ***not true*** of the pupil, circle the *0*. Please answer all items as well as you can, even if some do not seem to apply to this pupil.

0 = Not True (as far as you know) 1 = Somewhat or Sometimes True 2 = Very True or Often True

0 1 2 1. Acts too young for his/her age
0 1 2 2. Hums or makes other odd noises in class
0 1 2 3. Argues a lot
0 1 2 4. Fails to finish things he/she starts
0 1 2 5. There is very little that he/she enjoys
0 1 2 6. Defiant, talks back to staff
0 1 2 7. Bragging, boasting
0 1 2 8. Can't concentrate, can't pay attention for long
0 1 2 9. Can't get his/her mind off certain thoughts; obsessions (describe): ______________________
0 1 2 10. Can't sit still, restless, or hyperactive
0 1 2 11. Clings to adults or too dependent
0 1 2 12. Complains of loneliness
0 1 2 13. Confused or seems to be in a fog
0 1 2 14. Cries a lot
0 1 2 15. Fidgets
0 1 2 16. Cruelty, bullying, or meanness to others
0 1 2 17. Daydreams or gets lost in his/her thoughts
0 1 2 18. Deliberately harms self or attempts suicide
0 1 2 19. Demands a lot of attention
0 1 2 20. Destroys his/her own things
0 1 2 21. Destroys property belonging to others
0 1 2 22. Difficulty following directions
0 1 2 23. Disobedient at school
0 1 2 24. Disturbs other pupils
0 1 2 25. Doesn't get along with other pupils
0 1 2 26. Doesn't seem to feel guilty after misbehaving
0 1 2 27. Easily jealous
0 1 2 28. Breaks school rules
0 1 2 29. Fears certain animals, situations, or places other than school (describe): ______________________
0 1 2 30. Fears going to school
0 1 2 31. Fears he/she might think or do something bad
0 1 2 32. Feels he/she has to be perfect
0 1 2 33. Feels or complains that no one loves him/her
0 1 2 34. Feels others are out to get him/her
0 1 2 35. Feels worthless or inferior
0 1 2 36. Gets hurt a lot, accident-prone
0 1 2 37. Gets in many fights
0 1 2 38. Gets teased a lot
0 1 2 39. Hangs around with others who get in trouble
0 1 2 40. Hears sounds or voices that aren't there (describe): ______________________
0 1 2 41. Impulsive or acts without thinking
0 1 2 42. Would rather be alone than with others
0 1 2 43. Lying or cheating
0 1 2 44. Bites fingernails
0 1 2 45. Nervous, high-strung, or tense
0 1 2 46. Nervous movements or twitching (describe): ______________________
0 1 2 47. Overconforms to rules
0 1 2 48. Not liked by other pupils
0 1 2 49. Has difficulty learning
0 1 2 50. Too fearful or anxious
0 1 2 51. Feels dizzy or lightheaded
0 1 2 52. Feels too guilty
0 1 2 53. Talks out of turn
0 1 2 54. Overtired without good reason
0 1 2 55. Overweight

56. Physical problems ***without known medical cause:***

0 1 2 a. Aches or pains (***not*** stomach or headaches)
0 1 2 b. Headaches
0 1 2 c. Nausea, feels sick
0 1 2 d. Eye problems (***not*** if corrected by glasses) (describe): ______________________
0 1 2 e. Rashes or other skin problems
0 1 2 f. Stomachaches
0 1 2 g. Vomiting, throwing up
0 1 2 h. Other (describe): ______________________

Be sure you answered all items. Then see other side.

Please print. Be sure to answer all items.

0 = Not True (as far as you know) **1 = Somewhat or Sometimes True** **2 = Very True or Often True**

0 1 2 57. Physically attacks people

0 1 2 58. Picks nose, skin, or other parts of body (describe): ____________________
____

0 1 2 59. Sleeps in class

0 1 2 60. Apathetic or unmotivated

0 1 2 61. Poor school work

0 1 2 62. Poorly coordinated or clumsy

0 1 2 63. Prefers being with older children or youths

0 1 2 64. Prefers being with younger children

0 1 2 65. Refuses to talk

0 1 2 66. Repeats certain acts over and over; compulsions (describe): ____________________
____

0 1 2 67. Disrupts class discipline

0 1 2 68. Screams a lot

0 1 2 69. Secretive, keeps things to self

0 1 2 70. Sees things that aren't there (describe):
____
____

0 1 2 71. Self-conscious or easily embarrassed

0 1 2 72. Messy work

0 1 2 73. Behaves irresponsibly (describe): ____________________
____
____

0 1 2 74. Showing off or clowning

0 1 2 75. Too shy or timid

0 1 2 76. Explosive and unpredictable behavior

0 1 2 77. Demands must be met immediately, easily frustrated

0 1 2 78. Inattentive or easily distracted

0 1 2 79. Speech problem (describe): ____________________
____

0 1 2 80. Stares blankly

0 1 2 81. Feels hurt when criticized

0 1 2 82. Steals

0 1 2 83. Stores up too many things he/she doesn't need (describe): ____________________
____
____

0 1 2 84. Strange behavior (describe): ____________________
____

0 1 2 85. Strange ideas (describe): ____________________
____

0 1 2 86. Stubborn, sullen, or irritable

0 1 2 87. Sudden changes in mood or feelings

0 1 2 88. Sulks a lot

0 1 2 89. Suspicious

0 1 2 90. Swearing or obscene language

0 1 2 91. Talks about killing self

0 1 2 92. Underachieving, not working up to potential

0 1 2 93. Talks too much

0 1 2 94. Teases a lot

0 1 2 95. Temper tantrums or hot temper

0 1 2 96. Seems preoccupied with sex

0 1 2 97. Threatens people

0 1 2 98. Tardy to school or class

0 1 2 99. Smokes, chews, or sniffs tobacco

0 1 2 100. Fails to carry out assigned tasks

0 1 2 101. Truancy or unexplained absence

0 1 2 102. Underactive, slow moving, or lacks energy

0 1 2 103. Unhappy, sad, or depressed

0 1 2 104. Unusually loud

0 1 2 105. Uses alcohol or drugs for nonmedical purposes (*don't* include tobacco) (describe): ____________________
____

0 1 2 106. Overly anxious to please

0 1 2 107. Dislikes school

0 1 2 108. Is afraid of making mistakes

0 1 2 109. Whining

0 1 2 110. Unclean personal appearance

0 1 2 111. Withdrawn, doesn't get involved with others

0 1 2 112. Worries

113. Please write in any problems the pupil has that were not listed above.

0 1 2 ____________________

0 1 2 ____________________

0 1 2 ____________________

Please be sure you answered all items.

The SNAP-IV Teacher and Parent Rating Scale

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For each item, check the column that best describes this child:

	Not At All	Just A Little	Quite A Bit	Very Much
1. Often fails to give close attention to details or makes careless mistakes in schoolwork or tasks	______	______	______	______
2. Often has difficulty sustaining attention in tasks or play activities	______	______	______	______
3. Often does not seem to listen when spoken to directly	______	______	______	______
4. Often does not follow through on instructions and fails to finish schoolwork, chores, or duties	______	______	______	______
5. Often has difficulty organizing tasks and activities	______	______	______	______
6. Often avoids, dislikes, or reluctantly engages in tasks requiring sustained mental effort	______	______	______	______
7. Often loses things necessary for activities (e.g., toys, school assignments, pencils, or books)	______	______	______	______
8. Often is distracted by extraneous stimuli	______	______	______	______
9. Often is forgetful in daily activities	______	______	______	______
10. Often fidgets with hands or feet or squirms in seat	______	______	______	______
11. Often leaves seat in classroom or in other situations in which remaining seated is expected	______	______	______	______
12. Often runs about or climbs excessively in situations in which it is inappropriate	______	______	______	______
13. Often has difficulty playing or engaging in leisure activities quietly	______	______	______	______
14. Often is “on the go” or often acts as if “driven by a motor”	______	______	______	______
15. Often talks excessively	______	______	______	______
16. Often blurts out answers before questions have been completed	______	______	______	______
17. Often has difficulty awaiting turn	______	______	______	______
18. Often interrupts or intrudes on others (e.g., butts into conversations/games)	______	______	______	______

BRIEF
Teacher Form

Instructions:

On the following pages is a list of statements that describe children. We would like to know if the student has had problems with these behaviors over the past 6 months. Please answer all the items the best that you can. Please DO NOT SKIP ANY ITEMS. Think about the student as you reach each statement and circle your response:

N	if the behavior is	**Never** a problem
S	if the behavior is	**Sometimes** a problem
O	if the behavior is	**Often** a problem

N=Never **S=Sometimes** **O=Often**

1. Overreacts to small problems	N	S	O
2. When given three things to do, remembers only the first or last	N	S	O
3. Is not a self-starter	N	S	O
4. Cannot get a disappointment, scolding, or insult off his/her mind	N	S	O
5. Resists or has trouble accepting a different way to solve a problem with schoolwork, friends, chores, etc.	N	S	O
6. Becomes upset with new situations	N	S	O
7. Has explosive, angry outbursts	N	S	O
8. Has a short attention span	N	S	O

N=Never S=Sometimes O=Often

9. Needs to be told "no" or "stop that"	N	S	O
10. Needs to be told to begin a task even when willing	N	S	O
11. Loses lunch box, lunch money, permission slips, homework, etc.	N	S	O
12. Does not bring home homework, assignment sheets, materials, etc.	N	S	O
13. Acts upset by a change in plans	N	S	O
14. Is disturbed by change of teacher or class	N	S	O
15. Does not check work for mistakes	N	S	O
16. Cannot find clothes, glasses, shoes, toys, books, pencils, etc.	N	S	O
17. Has good ideas but cannot get them on paper	N	S	O
18. Has trouble concentrating on chores, schoolwork, etc.	N	S	O
19. Does not show creativity in solving a problem	N	S	O
20. Backpack is disorganized	N	S	O
21. Is easily distracted by noises, activity, sights, etc.	N	S	O
22. Makes careless errors	N	S	O
23. Forgets to hand in homework, even when completed	N	S	O
24. Resists change of routine, foods, places, etc.	N	S	O
25. Has trouble with chores or tasks that have more than one step	N	S	O
26. Has outbursts for little reason	N	S	O
27. Mood changes frequently	N	S	O
28. Needs help from adult to stay on task	N	S	O
29. Gets caught up in details and misses the big picture	N	S	O
30. Has trouble getting used to new situations (classes, groups, friends)	N	S	O
31. Forgets what he/she was doing	N	S	O
32. When sent to get something, forgets what he/she is supposed to get	N	S	O
33. Is unaware of how his/her behavior affects or bothers others	N	S	O
34. Has problems coming up with different ways of solving a problem	N	S	O
35. Has good ideas but does not get job done (lacks follow-through)	N	S	O
36. Leaves work incomplete	N	S	O
37. Becomes overwhelmed by large assignments	N	S	O
38. Does not think before doing	N	S	O
39. Has trouble finishing tasks (chores, homework)	N	S	O
40. Thinks too much about the same topic	N	S	O
41. Underestimates time needed to finish tasks	N	S	O
42. Interrupts others	N	S	O
43. Is impulsive	N	S	O
44. Does not notice when his/her behavior causes negative reactions	N	S	O
45. Gets out of seat at the wrong times	N	S	O
46. Is unaware of own behavior when in a group	N	S	O
47. Gets out of control more than his/her friends	N	S	O
48. Reacts more strongly to situations than other children	N	S	O
49. Starts assignments or chores at the last minute	N	S	O
50. Has trouble getting started on homework or chores	N	S	O
51. Mood is easily influenced by the situation	N	S	O

N=Never S=Sometimes O=Often

52. Does not plan ahead for school assignments	N	S	O
53. Gets stuck on one topic or activity	N	S	O
54. Has poor understanding of own strengths and weaknesses	N	S	O
55. Talks or plays too loudly	N	S	O
56. Written work is poorly organized	N	S	O
57. Acts too wild or "out of control"	N	S	O
58. Has trouble putting the brakes on his/her actions	N	S	O
59. Gets in trouble if not supervised by an adult	N	S	O
60. Has trouble remembering things, even for a few minutes	N	S	O
61. Work is sloppy	N	S	O
62. After having a problem, will stay disappointed for a long time	N	S	O
63. Does not take initiative	N	S	O
64. Angry or tearful outbursts are intense but end suddenly	N	S	O
65. Does not realize that certain actions bother others	N	S	O
66. Small events trigger big reactions	N	S	O
67. Cannot find things in room or school desk	N	S	O
68. Leaves a trail of belongings wherever he/she goes	N	S	O
69. Does not think of consequences before acting	N	S	O
70. Has trouble thinking of a different way to solve a problem when stuck	N	S	O
71. Leaves messes that others have to clean up	N	S	O
72. Becomes upset too easily	N	S	O
73. Has a messy desk	N	S	O
74. Has trouble waiting for turn	N	S	O
75. Does not connect doing tonight's homework with grades	N	S	O
76. Tests poorly even when he/she knows the correct answers	N	S	O
77. Does not finish long-term projects	N	S	O
78. Has poor handwriting	N	S	O
79. Has to be closely supervised	N	S	O
80. Has trouble moving from one activity to another	N	S	O
81. Is fidgety	N	S	O
82. Cannot stay on the same topic when talking	N	S	O
83. Blurts things out	N	S	O
84. Says the same things over and over	N	S	O
85. Talks at the wrong time	N	S	O
86. Does not come prepared for class	N	S	O

Medical History Questionnaire

[150]

1. What type of spina bifida do you have?

_____ Lipomeningocele (lipo)
_____ Myelomeningocele (MM)
_____ Other Please specify: ______________________
_____ Not sure

2. What is the level of your lesion?

_____ Sacral
_____ Lumbar
_____ Thoracic
_____ Not sure

3. Do you have a shunt? yes _____ no _____

    a. IF YES, has your shunt been infected? yes _____ no _____
    b. IF YES, have you had a shunt revision? yes _____ no _____
    c. IF your SHUNT HAS BEEN INFECTED, how many times? _____
    d. IF you have had a SHUNT REVISION, how many times? _____

4. Do you have seizures or take medication to prevent seizures?
yes _____ no _____

5. Are you able to do independent toileting?
yes _____ no _____

6. Are you on a catheterization schedule? yes _____ no _____

    a. If YES, do you do the catheterization (check one)?

_____ independently without reminding
_____ independently with reminding
_____ with partial assistance
_____ with complete assistance

    b. Have you ever had a bladder or urinary tract infection? yes _____ no _____

    c. How many times have you had a bladder or urinary tract infection? _______

    d. Have you had bladder stimulation? yes _____ no_____

7. Are you on a bowel program? [151]

yes _____ no _____

a. If YES, what type of bowel program (suppositories, diet, enemas, digital manipulation, etc.)?

____

____

____

b. If YOU ARE ON A BOWEL PROGRAM, do you do this program (check one)?

_____ independently without reminding
_____ independently with reminding
_____ with partial assistance
_____ with complete assistance

c. Have you had bowel stimulation? yes ____ no ____

8. Do you use diapers? yes _____ no _____

a. If YES, where do you use diapers (please check all that apply)?

_____ school
_____ home
_____ on outings
_____ all the time
_____ other? ____________________________________

9. Do you use braces? yes _____ no _____

a. If YES, what type (please check all that apply)?

_____ ankle-foot
_____ knee-ankle-foot
_____ hip-knee-ankle-foot
_____ reciprocating brace
_____ full control brace
_____ swivel walker
_____ parapodium
_____ twister cables
_____ night splint
_____ back brace

10. Do you use crutches? yes _____ no _____

11. Do you use a walker? yes _____ no _____ [152]

a. If YES, where do you use a walker (please check all that apply)?

_____ school
_____ home
_____ for long distance walking
_____ on outings
_____ all the time
_____ other? ____

12. Do you use a wheelchair? yes _____ no _____

a. If YES, where do you use a wheelchair (please check all that apply)?

_____ school
_____ home
_____ for long distance travel
_____ on outings
_____ all the time
_____ other? ____

13. If you use more than one mobility device, please write down the percentage of time that you use each device (please **make sure** that the percentages add up to 100%):

_____ % unassisted walking (no braces)
_____ % braces alone (no crutches or walker)
_____ % braces with crutches or walker
_____ % wheelchair
= 100 %

14. Please list your medications (include NAME OF MEDICATION, AMOUNT, HOW OFTEN TAKEN):

	Name of Medication	Amount	How Often Taken?
1.	____________________	__________	______________________
2.	____________________	__________	______________________
3.	____________________	__________	______________________
4.	____________________	__________	______________________
5.	____________________	__________	______________________
6.	____________________	__________	______________________
7.	____________________	__________	______________________
8.	____________________	__________	______________________
9.	____________________	__________	______________________
10.	____________________	__________	______________________

15. Please list your surgeries over the **past two years** (include year of surgery, reason for surgery; examples include: shunt revision, shunt replacement, leg surgery, back surgery, tethered cord, etc.):

	Year of Surgery	Reason for Surgery
1.		
2.		
3.		
4.		
5.		
6.		
7.		
8.		
9.		
10.		
11.		
12.		
13.		
14.		
15.		

16. What changes have occurred in your health **OVER THE PAST TWO YEARS**?

17. In the past year, how many visits have you had with a primary care physician (regular family doctor)? ______________________ [154]

Please describe the reason(s) for these visits: ___________________________________

____

____

18. In the past year, how many visits have you had with a urologist? _________________

Please describe the reason(s) for these visits: ___________________________________

____

____

19. In the past year, how many visits have you had with an orthopedist? _______________

Please describe the reason(s) for these visits: ___________________________________

____

____

20. In the past year, how many visits have you had with a neurologist? _______________

Please describe the reason(s) for these visits: ___________________________________

____

____

21. In the past year, how many visits have you had with a physical or occupational therapist?

____

If you have visited a physical or occupational therapist, which one did you visit?
_____ Physical therapist
_____ Occupational therapist
_____ Both

Please describe the reason(s) for these visits: ___________________________________

____

____[155]

22. In the past year, on how many occasions have you visited the emergency room? ______

Please describe the reason(s) for these visits: ___________________________________

____

____

23. In the past year, how many visits have you had with any other type of health care professional? ____

Type of health professional seen: ____

____

Please describe the reason(s) for these visits: ___________________________________

____

____

24. In the past year, how many times have you been hospitalized? ____________________

Length of stay ____

Please describe the reason(s) for these hospitalizations: __________________________

____

____

Please print your answers.

ADULT SELF-REPORT FOR AGES 18-59

For office use only
ID#

Please fill out this form to reflect ***your*** views, even if other people might not agree. You need not spend a lot of time on any item. Feel free to print additional comments. ***Be sure to answer all items.***

I. FRIENDS:

A. About how many close friends do you have? (Do not include family members.)

☐ **None** ☐ **1** ☐ **2 or 3** ☐ **4 or more**

B. About how many times a month do you have contact with any of your close friends? (Include in-person contacts, phone, letters, e-mail.)

☐ **Less than 1** ☐ **1 or 2** ☐ **3 or 4** ☐ **5 or more**

C. How well do you get along with your close friends?

☐ **Not as well as I'd like** ☐ **Average** ☐ **Above average** ☐ **Far above average**

D. About how many times a month do any friends or family visit you?

☐ **Less than 1** ☐ **1 or 2** ☐ **3 or 4** ☐ **5 or more**

II. SPOUSE OR PARTNER:

What is your marital status?

☐ **Never been married**
☐ **Married, living with spouse**
☐ **Widowed**
☐ **Married but separated from spouse**
☐ **Divorced**
☐ **Other—please describe:** ____________________

At any time in the past 6 months, did you live with your spouse or with a partner?

☐ **No—please skip to page 2.**

☐ **Yes**—Circle ***0, 1,*** or **2** beside items A-H to describe your relationship ***during the past 6 months:***

0 = Not True **1 = Somewhat or Sometimes True** **2 = Very True or Often True**

0 1 2 A. I get along well with my spouse or partner
0 1 2 B. My spouse or partner and I have trouble sharing responsibilities
0 1 2 C. I feel satisfied with my spouse or partner
0 1 2 D. My spouse or partner and I enjoy similar activities
0 1 2 E. My spouse or partner and I *disagree* about living arrangements, such as where we live
0 1 2 F. I have trouble with my spouse or partner's family
0 1 2 G. I like my spouse or partner's friends
0 1 2 H. My spouse or partner's behavior annoys me

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Please be sure you have answered all items.
Then see other side.

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Please print. Be sure to answer all items.

III. FAMILY:

Compared with others, how well do you:		Worse than Average	Variable or Average	Better than Average	No Contact
A. Get along with your brothers?	☐ I have no brothers	☐	☐	☐	☐
B. Get along with your sisters?	☐ I have no sisters	☐	☐	☐	☐
C. Get along with your mother?	☐ Mother is deceased	☐	☐	☐	☐
D. Get along with your father?	☐ Father is deceased	☐	☐	☐	☐
E. Get along with your biological or adopted children?	☐ I have no children				
1. Oldest child	☐ Not applicable	☐	☐	☐	☐
2. 2nd oldest child	☐ Not applicable	☐	☐	☐	☐
3. 3rd oldest child	☐ Not applicable	☐	☐	☐	☐
4. Other children	☐ Not applicable	☐	☐	☐	☐
F. Get along with your stepchildren?	☐ I have no stepchildren	☐	☐	☐	☐

IV. JOB: ***At any time in the past 6 months,*** did you have any paid jobs (including self-employment and military service)?

☐ **No—please skip to Section V.**

☐ **Yes—please describe your job(s):** ______________________

Circle ***0, 1,*** or **2** beside items A-I to describe your work experience ***during the past 6 months:***

0 = Not True **1 = Somewhat or Sometimes True** **2 = Very True or Often True**

0 1 2 A. I work well with others

0 1 2 B. I have trouble getting along with bosses

0 1 2 C. I do my work well

0 1 2 D. I have trouble finishing my work

0 1 2 E. I am satisfied with my work situation

0 1 2 F. I do things that may cause me to lose my job

0 1 2 G. I stay away from my job even when I'm not sick or not on vacation

0 1 2 H. My job is too stressful for me

0 1 2 I. I worry too much about work

V. EDUCATION: ***At any time in the past 6 months,*** did you attend school, college, or any other educational or training program?

☐ **No—please skip to Section VI.**

☐ **Yes**—what kind of school or program? ______________________

What degree or diploma are you seeking? ______________ Major? ______________

When do you expect to receive your degree or diploma? ______________________

Circle ***0, 1,*** or **2** beside items A-E to describe your educational experience ***during the past 6 months:***

0 = Not True **1 = Somewhat or Sometimes True** **2 = Very True or Often True**

0 1 2 A. I get along well with other students

0 1 2 B. I achieve what I am capable of

0 1 2 C. I have trouble finishing assignments

0 1 2 D. I am satisfied with my educational situation

0 1 2 E. I do things that may cause me to fail

VI. Do you have any illness, disability, or handicap? ☐ **No** ☐ **Yes—please describe:**

VII. Please describe your concerns or worries about family, work, education, or other things: ☐ **No concerns**

VIII. Please describe the best things about yourself:

Please be sure you have answered all items.

Please print your answers. Be sure to answer all items.

IX. Below is a list of items that describe people. For each item, please circle *0, 1,* or *2* to describe yourself *over the past 6 months.* Please answer all items as well as you can, even if some do not seem to apply to you.

0 = Not True **1 = Somewhat or Sometimes True** **2 = Very True or Often True**

0 1 2 1. I am too forgetful
0 1 2 2. I make good use of my opportunities
0 1 2 3. I argue a lot
0 1 2 4. I work up to my ability
0 1 2 5. I blame others for my problems
0 1 2 6. I use drugs (other than alcohol and nicotine) for nonmedical purposes (describe): ________

____

0 1 2 7. I brag
0 1 2 8. I have trouble concentrating or paying attention for long
0 1 2 9. I can't get my mind off certain thoughts (describe): ________________

____

0 1 2 10. I have trouble sitting still
0 1 2 11. I am too dependent on others
0 1 2 12. I feel lonely
0 1 2 13. I feel confused or in a fog
0 1 2 14. I cry a lot
0 1 2 15. I am pretty honest
0 1 2 16. I am mean to others
0 1 2 17. I daydream a lot
0 1 2 18. I deliberately try to hurt or kill myself
0 1 2 19. I try to get a lot of attention
0 1 2 20. I damage or destroy my things
0 1 2 21. I damage or destroy things belonging to others
0 1 2 22. I worry about my future
0 1 2 23. I break rules at work or elsewhere
0 1 2 24. I don't eat as well as I should
0 1 2 25. I don't get along with other people
0 1 2 26. I don't feel guilty after doing something I shouldn't
0 1 2 27. I am jealous of others
0 1 2 28. I get along badly with my family
0 1 2 29. I am afraid of certain animals, situations, or places (describe): ________________

____

0 1 2 30. My relations with the opposite sex are poor
0 1 2 31. I am afraid I might think or do something bad
0 1 2 32. I feel that I have to be perfect
0 1 2 33. I feel that no one loves me
0 1 2 34. I feel that others are out to get me
0 1 2 35. I feel worthless or inferior
0 1 2 36. I accidentally get hurt a lot, accident-prone

0 1 2 37. I get in many fights
0 1 2 38. My relations with neighbors are poor
0 1 2 39. I hang around people who get in trouble
0 1 2 40. I hear sounds or voices that other people think aren't there (describe): ________________

____

0 1 2 41. I am impulsive or act without thinking
0 1 2 42. I would rather be alone than with others
0 1 2 43. I lie or cheat
0 1 2 44. I feel overwhelmed by my responsibilities
0 1 2 45. I am nervous or tense
0 1 2 46. Parts of my body twitch or make nervous movements (describe): ________________

____

0 1 2 47. I lack self-confidence
0 1 2 48. I am not liked by others
0 1 2 49. I can do certain things better than other people
0 1 2 50. I am too fearful or anxious
0 1 2 51. I feel dizzy or lightheaded
0 1 2 52. I feel too guilty
0 1 2 53. I have trouble planning for the future
0 1 2 54. I feel tired without good reason
0 1 2 55. My moods swing between elation and depression
56. Physical problems ***without known medical cause:***
0 1 2 a. Aches or pains (***not*** stomach or headaches)
0 1 2 b. Headaches
0 1 2 c. Nausea, feel sick
0 1 2 d. Problems with eyes (***not*** if corrected by glasses) (describe): ________________

____

0 1 2 e. Rashes or other skin problems
0 1 2 f. Stomachaches
0 1 2 g. Vomiting, throwing up
0 1 2 h. Heart pounding or racing
0 1 2 i. Numbness or tingling in body parts
0 1 2 57. I physically attack people
0 1 2 58. I pick my skin or other parts of my body (describe): ________________

____

0 1 2 59. I fail to finish things I should do
0 1 2 60. There is very little that I enjoy
0 1 2 61. My work performance is poor
0 1 2 62. I am poorly coordinated or clumsy

Please be sure you have answered all items. Then see other side.

Please print your answers. Be sure to answer all items.

0 = Not True **1 = Somewhat or Sometimes True** **2 = Very True or Often True**

0 1 2 63. I would rather be with older people than with people of my own age

0 1 2 64. I have trouble setting priorities

0 1 2 65. I refuse to talk

0 1 2 66. I repeat certain acts over and over (describe): ______________________

____

0 1 2 67. I have trouble making or keeping friends

0 1 2 68. I scream or yell a lot

0 1 2 69. I am secretive or keep things to myself

0 1 2 70. I see things that other people think aren't there (describe): ______________

____

0 1 2 71. I am self-conscious or easily embarrassed

0 1 2 72. I worry about my family

0 1 2 73. I meet my responsibilities to my family

0 1 2 74. I show off or clown

0 1 2 75. I am too shy or timid

0 1 2 76. My behavior is irresponsible

0 1 2 77. I sleep more than most other people during day and/or night (describe):

____

0 1 2 78. I have trouble making decisions

0 1 2 79. I have a speech problem (describe):

____

0 1 2 80. I stand up for my rights

0 1 2 81. My behavior is very changeable

0 1 2 82. I steal

0 1 2 83. I am easily bored

0 1 2 84. I do things that other people think are strange (describe): ______________

____

0 1 2 85. I have thoughts that other people would think are strange (describe): __________

____

0 1 2 86. I am stubborn, sullen, or irritable

0 1 2 87. My moods or feelings change suddenly

0 1 2 88. I enjoy being with people

0 1 2 89. I rush into things without considering the risks

0 1 2 90. I drink too much alcohol or get drunk

0 1 2 91. I think about killing myself

0 1 2 92. I do things that may cause me trouble with the law (describe): ____________

____

0 1 2 93. I talk too much

0 1 2 94. I tease others a lot

0 1 2 95. I have a hot temper

0 1 2 96. I think about sex too much

0 1 2 97. I threaten to hurt people

0 1 2 98. I like to help others

0 1 2 99. I dislike staying in one place for very long

0 1 2 100. I have trouble sleeping (describe): ________

____

0 1 2 101. I stay away from my job even when I'm not sick or not on vacation

0 1 2 102. I don't have much energy

0 1 2 103. I am unhappy, sad, or depressed

0 1 2 104. I am louder than others

0 1 2 105. People think I am disorganized

0 1 2 106. I try to be fair to others

0 1 2 107. I feel that I can't succeed

0 1 2 108. I tend to lose things

0 1 2 109. I like to try new things

0 1 2 110. I wish I were of the opposite sex

0 1 2 111. I keep from getting involved with others

0 1 2 112. I worry a lot

0 1 2 113. I worry about my relations with the opposite sex

0 1 2 114. I fail to pay my debts or meet other financial responsibilities

0 1 2 115. I feel restless or fidgety

0 1 2 116. I get upset too easily

0 1 2 117. I have trouble managing money or credit cards

0 1 2 118. I am too impatient

0 1 2 119. I am not good at details

0 1 2 120. I drive too fast

0 1 2 121. I tend to be late for appointments

0 1 2 122. I have trouble keeping a job

0 1 2 123. I am a happy person

124. ***In the past 6 months,*** about how many times per day did you use tobacco (including smokeless tobacco)? __________ times per day.

125. ***In the past 6 months,*** on how many days were you drunk? __________ days.

126. ***In the past 6 months,*** on how many days did you use drugs for nonmedical purposes (including marijuana, cocaine, and other drugs, except alcohol and nicotine)? __________ days.

BRIEF-A

Instructions
On the following pages is a list of statements. We would like to know if you have had problems with these behaviors over the past month. Please answer all the items the best that you can. Please DO NOT SKIP ANY ITEMS. Indicate your response by circling

N	If the behavior is	**Never** a problem
S	If the behavior is	**Sometimes** a problem
O	If the behavior is	**Often** a problem

For example, if you **never** have trouble making decisions, you would circle **N** for this item:

I have trouble making decisions [✓ N] S O

If you make a mistake or want to change your answer DO NOT ERASE. Draw an "X" through the answer you want to change, and then circle the correct answer:

I have trouble making decisions ~~N~~ [✓ S] O

During the past month, how often has each of the following behaviors been a problem?

N = Never **S = Sometimes** **O = Often** [161]

1. I have angry outbursts **N S O**
2. I make careless errors when completing tasks **N S O**
3. I am disorganized **N S O**
4. I have trouble concentrating on tasks (such as chores, reading, or work) **N S O**
5. I tap my fingers or bounce my legs **N S O**
6. I need to be reminded to begin a task even when I am willing **N S O**
7. I have a messy closet **N S O**
8. I have trouble changing from one activity or task to another **N S O**
9. I get overwhelmed by large tasks **N S O**
10. I forget my name **N S O**
11. I have trouble with jobs or tasks that have more than one step **N S O**
12. I overreact emotionally **N S O**
13. I don’t notice when I cause others to feel bad or get mad until it is too late **N S O**
14. I have trouble getting ready for the day **N S O**
15. I have trouble prioritizing activities **N S O**
16. I have trouble sitting still **N S O**
17. I forget what I am doing in the middle of things **N S O**
18. I don’t check my work for mistakes **N S O**
19. I have emotional outbursts for little reason **N S O**
20. I lie around the house a lot **N S O**

During the past month, how often has each of the following behaviors been a problem?

N = Never **S = Sometimes** **O = Often**

21. I start tasks (such as cooking, projects) without the right materials	N	S	O
22. I have trouble accepting different ways to solve problems with work, friends or tasks	N	S	O
23. I talk at the wrong time	N	S	O
24. I misjudge how difficult or easy tasks will be	N	S	O
25. I have problems getting started on my own	N	S	O
26. I have trouble staying on the same topic when talking	N	S	O
27. I get tired	N	S	O
28. I react more emotionally to situations than my friends	N	S	O
29. I have problems waiting my turn	N	S	O
30. People say that I am disorganized	N	S	O
31. I lose things (such as keys, money, wallet, homework, etc.)	N	S	O
32. I have trouble thinking of a different way to solve a problem when stuck	N	S	O
33. I overreact to small problems	N	S	O
34. I don't plan ahead for future activities	N	S	O
35. I have a short attention span	N	S	O
36. I make inappropriate sexual comments	N	S	O
37. When people seem upset with me, I don't understand why	N	S	O
38. I have trouble counting to three	N	S	O
39. I have unrealistic goals	N	S	O
40. I leave the bathroom a mess	N	S	O

During the past month, how often has each of the following behaviors been a problem?

N = Never **S = Sometimes** **O = Often**

41. I make careless mistakes	**N**	**S**	**O**
42. I get emotionally upset easily	**N**	**S**	**O**
43. I make decisions that get me into trouble (legally, financially, socially)	**N**	**S**	**O**
44. I am bothered by having to deal with changes	**N**	**S**	**O**
45. I have difficulty getting excited about things	**N**	**S**	**O**
46. I forget instructions easily	**N**	**S**	**O**
47. I have good ideas but cannot get them on paper	**N**	**S**	**O**
48. I make mistakes	**N**	**S**	**O**
49. I have trouble getting started on tasks	**N**	**S**	**O**
50. I say things without thinking	**N**	**S**	**O**
51. My anger is intense but ends quickly	**N**	**S**	**O**
52. I have trouble finishing tasks (such as chores, work)	**N**	**S**	**O**
53. I start things at the last minute (such as assignments, chores, tasks)	**N**	**S**	**O**
54. I have difficulty finishing a task on my own	**N**	**S**	**O**
55. People say that I am easily distracted	**N**	**S**	**O**
56. I have trouble remembering things, even for a few minutes (such as directions, phone numbers)	**N**	**S**	**O**
57. People say that I am too emotional	**N**	**S**	**O**
58. I rush through things	**N**	**S**	**O**
59. I get annoyed	**N**	**S**	**O**
60. I leave my room or home a mess	**N**	**S**	**O**

During the past month, how often has each of the following behaviors been a problem?

N = Never **S = Sometimes** **O = Often**

61. I get disturbed by unexpected changes in my daily routine	**N**	**S**	**O**
62. I have trouble coming up with ideas for what to do with my free time	**N**	**S**	**O**
63. I don't plan ahead for tasks	**N**	**S**	**O**
64. People say that I don't think before acting	**N**	**S**	**O**
65. I have trouble finding things in my room, closet or desk	**N**	**S**	**O**
66. I have problems organizing activities	**N**	**S**	**O**
67. After having a problem, I don't get over it easily	**N**	**S**	**O**
68. I have trouble doing more than one thing at a time	**N**	**S**	**O**
69. My mood changes frequently	**N**	**S**	**O**
70. I don't think about consequences before doing something	**N**	**S**	**O**
71. I have trouble organizing work	**N**	**S**	**O**
72. I get upset quickly or easily over little things	**N**	**S**	**O**
73. I am impulsive	**N**	**S**	**O**
74. I don't pick up after myself	**N**	**S**	**O**
75. I have problems completing my work	**N**	**S**	**O**

WIAL-C

For the following, first decide what is true for you—the one described on the left or right— and then indicate whether this is just sort of true or really true for you. Thus, for each item, check **only one** of four spaces.

Sample Sentence

	Really True For Me	Sort Of True For Me				Sort Of True For Me	Really True For Me
(a)	_____	_____	Some kids would rather play outdoors in their spare time	BUT	Other kids would rather watch T.V.	__X__	_____
1.	_____	_____	Some kids find it *hard* to make friends	BUT	Other kids find it’s pretty *easy* to make friends	_____	_____
2.	_____	_____	Some kids have *a lot* of friends	BUT	Other kids *don’t* have very many friends	_____	_____
3.	_____	_____	Some kids would like to have a lot more friends	BUT	Other kids have as many friends as they want	_____	_____
4.	_____	_____	Some kids are always doing things with *a lot* of kids	BUT	Other kids usually do things by *themselves*	_____	_____
5.	_____	_____	Some kids wish that more people their age liked them	BUT	Other kids feel that most people their age *do* like them	_____	_____
6.	_____	_____	Some kids are *popular* with others their age	BUT	Other kids are *not* very popular	_____	_____

ID# [166]

Date:

PedsQL™

Young Adult Quality of Life Inventory

Version 4.0

YOUNG ADULT REPORT (ages **18-25**)

DIRECTIONS

On the following page is a list of things that might be a problem for you. Please tell us **how much of a problem** each one has been for you during the **past ONE month** by circling:

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

*In the past **ONE month**, how much of a **problem** has this been for you …* [167]

ABOUT MY HEALTH AND ACTIVITIES *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard for me to walk more than one block	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do sports activity or exercise	0	1	2	3	4
4. It is hard for me to lift something heavy	0	1	2	3	4
5. It is hard for me to take a bath or shower by myself	0	1	2	3	4
6. It is hard for me to do chores around the house	0	1	2	3	4
7. I hurt or feel pain	0	1	2	3	4
8. I have low energy	0	1	2	3	4

ABOUT MY FEELINGS *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad or blue	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4

HOW I GET ALONG WITH OTHERS *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. I have trouble getting along with other young adults	0	1	2	3	4
2. Other young adults do not want to be my friend	0	1	2	3	4
3. Other young adults tease me	0	1	2	3	4
4. I cannot do things that others my age can do	0	1	2	3	4
5. It is hard to keep up with my peers	0	1	2	3	4

ABOUT MY WORK/STUDIES *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard to pay attention at work or school	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my work or studies	0	1	2	3	4
4. I miss work or school because of not feeling well	0	1	2	3	4
5. I miss work or school to go to the doctor or hospital	0	1	2	3	4

ID # _______________

Medical Chart Review Form

Patient Name: ____ DOB: ____________________

Parent Names: ____

Medical Chart #: ____________________________

Home Phone #: ____________________________ Work Phone #: ________________________

Work Phone #: ________________________

Home Address: ____

____

____

____

Gender: ___________________ Ethnicity / Race: ______________________

Type of Spina Bifida (e.g., myelomeningocele, meningocele, lipomeningocele, lipomyelomeningocele, lipoma) ____

Chiari Malformation: yes _________ no ___________

If yes, Type 1 ____________ Type 2 ___________

Any other medical diagnoses (e.g., blindness, diabetes, fetal alcohol syndrome, etc.):

Any psychiatric diagnoses (e.g., ADHD, depression, autism):

Complicating factors during pregnancy (e.g., infection, preterm labor, hyptertension, pregnancy induced diabetes, pre-eclampsia):

Complicating factors during delivery/labor (e.g, premature delivery, long labor, breech, Caesarian delivery, infection, lack of oxygen, jaundice, intensive care):

Apgar score at birth: ____________ 1 minute ____________ 5 minutes

Weight at birth: ____________ lbs ____________ ounces or ____________ grams

Length at birth: ____________ inches or ____________ cm

IQ INFORMATION (Provide date, age of child, test, and scores. Examples of possible tests: McCarty, Stanford-Binet, WISC-IV, WPPSI, Bailey):

Date of Testing	Age of Child	Test(s) Given	Scores

ACHIEVEMENT TEST INFORMATION (Provide date, age of child, test, and scores. Examples of possible tests: WRAT-III, WIAT, Woodcock-Johnson):

Date of Testing	Age of Child	Test(s) Given	Scores

LESION LEVEL INFORMATION (Lesion levels for right side and left side may differ. Please list date of report and who reported the lesion level):

Date of Report	Who Reported?	Lesion Level Information

SHUNT STATUS: yes _____________ no ______________

Type of shunt (e.g., ventriculoperitoneal, ventriculoatrial, lumboperitoneal, other)

____

Location of shunt: Left __________ Right _______ Bilateral _______

Shunt revisions: yes _______ no _______

Dates of shunt revisions: ____

____

Total number of shunt revisions: ____

Shunt infections: yes _______ no _______

Dates of shunt infections ____

____

Total number of shunt infections: ____________________________________

Other comments regarding shunts: ___________________________________

____

NON-SHUNT RELATED SURGERY INFORMATION (Provide date, age of child, type of surgery, any complications. Possible surgeries: spinal closure, shunt placement, tethered cord, orthopedic surgery, chiari operation, urological surgery)

Date of Surgery	Age of Child	Type of Surgery	Any complications noted?

UROLOGICAL HISTORY

Urinary tract infections? yes _______ no _______

If yes, how many: ____

Kidney reflux? yes _______ no ________

Clean intermittent catheterization? yes _______ no ________

ORTHOPEDIC HISTORY

Scoliosis? yes ______ no _______ Surgery for scoliosis? yes _______ no _______

Kyphosis? yes ______ no _______ Surgery for kyphosis? yes _______ no _______

Lordosis? yes ______ no _______ Surgery for lordosis? yes _______ no _______

HISTORY OF SEIZURES

Prior to 1st year of life? yes ______ no _______

After 1st year of life? yes ______ no _______

Medications for seizures? yes ______ no _______

If yes, what medications? ____

____

VISION DISORDERS

Any vision disorders (e.g., oculomotor disorder, strabismus, amblyopia, nystagmus)?

yes ______ no _______

If yes, what type? ____

____

If yes, how treated? ____

____

ANY OTHER NOTEWORTHY COMMENTS/NOTES FROM THE CHART (e.g., child compliance, self-care skills, catheterization, bowel program, seizures, medication, ambulation, no-shows for appointments)

REFERENCE LIST

Achenbach, T. M., & Rescorla, L. A. (2001). *ASEBA school-age forms & profiles: An integrated system of multi-informant assessment*. Burlington, VT: ASEBA.

Achenbach, T. M., & Rescorla, L. A. (2003). *Manual for the ASEBA Adult Forms & Profiles*. Burlington, VT: University of Vermont, Research Center for Children, Youth, and Families.

Ackerman, B. P., Izard, C. E., Schoff, K., Youngstrom, E. A., & Kogos, J. (1999). Contextual risk, caregiver emotionality, and the problem behaviors of six- and seven-year-old children from economically disadvantaged families. *Child Development, 70*(6), 1415–1427. doi: 10.1111/1467-8624.00103

Adler, N. E., & Stewart, J. (2010). Health disparities across the lifespan: Meaning, methods, and mechanisms. *Annals of The New York Academy of Sciences, 1186*, 5–23. doi: 10.1111/j.1749-6632.2009.05337.x

Agopian, A. J., Tinker, S. C., Lupo, P. J., Canfield, M. A., Mitchell, L. E., & National Birth Defects Prevention Study. (2013). Proportion of neural tube defects attributable to known risk factors. *Birth Defects Research Part A: Clinical and Molecular Teratology, 97*(1), 42–46. doi: 10.1002/bdra.23100.

Aiken, L. S., & West, S. G. (1991). *Multiple regression: Testing and interpreting interactions*. Newbury Park: Sage Publishers.

American Academy of Pediatrics [AAP]. (2010). Health equity and children's rights. *Pediatrics, 125*(4), 1018–1021. doi: 10.1542/peds.2010-0235

American Psychiatric Association [APA]. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, D.C.: American Psychiatric Association.

American Psychological Association Task Force on Socioeconomic Status [APATFSES]. (2007). *Report of the APA Task Force on Socioeconomic Status.* Washington, DC: American Psychological Association

Ammerman, R. T., Kane, V. R., Slomka, G. T., Reigal, D. H., Franzen, M. D., & Gadow, K. D. (1998). Psychiatric symptomatology and family functioning in children and adolescents with spina bifida. *Journal of Clinical Psychology in Medical Settings, 5*(4), 449–465. doi: 10.1023/A:1026211028595

Appleyard, K., Egeland, B., van Dulmen, M. H. M., & Sroufe, L. A. (2005). When more is not better: The role of cumulative risk in child behavior outcomes. *Journal of Child Psychology and Psychiatry, 46*(3), 235–245 doi: 10.1111/j.1469-7610.2004.00351.x

Atkinson, L., Beitchman, J., Gonzalez, A., Young, A., Wilson, B., Escobar, M., … & Villani, V. (2015). Cumulative risk, cumulative outcome: A 20-year longitudinal study. *PLoS ONE, 10*(6), e0127650. doi:10.1371/journal.pone.0127650

Bartonek, A., Saraste, H., & Danielsson, A. (2012). Health-related quality of life and ambulation in children with myelomeningocele in a Swedish population. *Acta Paediatrica, 101*, 953–956. doi: 10.1111/j.1651-2227.2012.02742.x

Becker, S. P., Ramsey, R. R., & Byars, K. C. (2015). Convergent validity of the child behavior checklist sleep items with validated sleep measures and sleep disorder diagnoses in children and adolescents referred to a sleep disorders center. *Sleep Medicine, 16*(1), 79–86. doi: 10.1016/j.sleep.2014.09.008

Bellin, M. H., Zabel, T. A., Dicianno, B. E., Levey, E., Garver, K., Linroth, R., & Braun, P. (2010). Correlates of depressive and anxiety symptoms in young adults with spina bifida. *Journal of Pediatric Psychology, 35*(7), 778–789. doi: 10.1093/jpepsy/jsp094

Belsky, J., Bell, B., Bradley, R. H., Stallard, N., & Stewart-Brown, S. L. (2007). Socioeconomic risk, parenting during the preschool years and child health age 6 years. *European Journal of Public Health, 17*(5), 508–513. doi:10.1093/eurpub/ckl261

Bemis, H., Yarboi, J., Gerhardt, C. A., Vannatta, K., Desjardins, L., Murphy, L. K., … & Compas, B. E. (2015). Childhood cancer in context: Sociodemographic factors, stress, and psychological distress among mothers and children. *Journal of Pediatric Psychology, 40*(8), 733–743. doi: 10.1093/jpepsy/jsv024

Berry, J. G., Bloom, S., Foley, S., & Palfrey, J. S. (2010). Health inequity in children and youth with chronic health conditions. *Pediatrics, 126*(3), 111–119. doi: 10.1542/peds.2010-1466D

Bier, J. B., Morales, Y., Liebling, J., Geddes, L., & Kim, E. (1997). Medical and social factors associated with cognitive outcome in individuals with myelomeningocele. *Developmental Medicine & Child Neurology, 39,* 263–266. doi: 10.1111/j.1469-8749.1997.tb07423.x

Bisaro, D. L., Bidonde, J., Kane, K. J., Bergsma, S., & Musselman, K. E. (2015). Past and current use of walking measures for children with spina bifida: A systematic review. *Archives of Physical Medicine and Rehabilitation, 96*(8), 1533–1543. doi: 10.1016/j.apmr.2015.04.014

Blanz, B., Schmidt, M. H., & Esser, G. (1991). Familial adversities and child psychiatric disorders. *Journal of Child Psychiatry and Psychology, 32*(6), 939–950. doi: 10.1111/j.1469-7610.1991.tb01921.x

Blum, R. W., Resnick, M. D., Nelson, R., & St. Germain, A. (1991). Family and peer issues among adolescents with spina bifida and cerebral palsy. *Pediatrics, 88*(2), 280–285. doi: 10.1177/089801010202000307

Bol, K. A., Collins, J. S., & Kirby, R. S. (2006). Survival of infants with neural tube defects in the presence of folic acid fortification. *Pediatrics, 117*(3), 803–813. doi: 10.1542/peds.2005-1364

Borschuck, A. P., & Everheart, R. S. (2015). Health disparities among youth with type 1 diabetes: A systematic review of the current literature. *Families, Systems, & Health, 33*(3), 297–313. doi: /10.1037/fsh0000134

Boulet, S. L., Yang, Q., Mai, C., Kirby, C. S., Collins, J. S., Robbins, J. M. … National Birth Defects Prevention Network (2008). Trends in the postfortification prevalence of spina bifida and anencephaly in the United States. *Birth Defects Research Part A: Clinical Molecular Teratolgy, 82*(7), 527–532. doi: 10.1002/bdra.20468

Bradley, R. H., & Corwyn, R. F. (2002). Socioeconomic status and child development. *Annual Review of Psychology, 53,* 371–399. doi: 10.1146/annurev.psych.53.100901.135233

Braveman, P. A., Cubbin, C., Egerter, S., Chideya, S., Marchi, K. S., Metzler, M., & Posner, S. (2005). Socioeconomic status in health research: one size does not fit all. *JAMA, 294*(22), 2879–2888. doi: 10.1001/jama.294.22.2879

Braveman, P., Cubbin, C., Marchi, K., Ecerter, S., & Chaves, G. (2001). Measuring socioeconomic status/position in studies of racial/ethnic disparities: Maternal and infant health. *Public Health Reports, 116*(5), 449–461. doi: 10.1093/phr/116.5.449

Braveman, P., & Gottlieb, L. (2014). The social determinants of health: It's time to consider the causes of the causes. *Public Health Records, 129*(2), 19–31. doi: 10.1177/00333549141291S206

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist, 32*(7), 513–531. doi: 10.1037/0003-066X.32.7.513

Bronfrenbrenner, U. (2005). The bioecological theory of human development. In U. Bronfenbrenner (Ed.), *Making human beings: Bioecological perspectives on human development* (pp. 3–15). Thousand Oaks, CA: Sage.

Bronfenbrenner, U., & Morris, P. A. (1998). The ecology of developmental processes. In W. Damon & R. Lerner (Eds.), *Handbook of child psychology* (Vol. 4, pp.999–1058). New York, NY: Wiley.

Bronfenbrenner, U., & Morris, P. A. (2006). The bioecological model of human development. In R. M. Lerner (Ed.) *Theoretical models of human development* (6th ed., Vol. 1, pp. 793–828). Hoboken, NJ: Wiley.

Buffart, L. M., van den Berg-Emons, R. J., Burdorf, A., Janssen, W. G., Stam, H. J., & Roebroeck, M. E. (2008). Cardiovascular disease risk factors and the relationships with physical activity, aerobic fitness, and body fat in adolescents and young adults with myelomeningocele. *Archives of Physical Medicine and Rehabilitation, 89*(11), 2167–2173. doi: 10.1016/j.apmr.2008.04.015

Bukowski, W. M., Hoza, B., & Boivin, M. (1994). Measuring friendship quality during pre- and early adolescence: The development and psychometric properties of the friendship qualities scales. *Journal of Social and Personal Relationships, 11*(3), 471–484. doi: 10.1177/0265407594113011

Buran, C. F., Sawin, K. J., Brei, T. J., & Fastenau, P. S. (2004). Adolescents with myelomeningocele: Activities, beliefs, expectations, and perceptions. *Developmental Medicine & Child Neurology*, *46*(4), 244–252. doi: 10.1017/S0012162204000404

Cate, I. M., Kennedy, C., & Stevenson, J. (2002). Disability and quality of life in spina bifida and hydrocephalus. *Developmental Medicine & Child Neurology*, *44*(5), 317–322. doi: 10.1017/S0012162201002146

Cavell, T. A. (1990). Social adjustment, social performance, and social skills: A tri-component model of social competence. *Journal of Clinical Child Psychology*, *19*(2),111–122. doi:10.1207/s15374424jccp1902_2

Center for Disease Control and Prevention [CDC]. (2009). Racial/ethnic differences in the birth prevalence of spina bifida-United States, 1995–2005. *MMWR, 57*(53), 1409–1413. Retrieved from: http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5753a2.htm

Centers for Disease Control and Prevention [CDC]. (1999). *Youth risk behavior surveillance system: 1999 youth risk behavior survey*. Retrieved from http://www.cdc.gov/nccdphp/dash/yrbs/survey99.htm.

Center for Disease Control and Prevention [CDC]. (2011). *Spina bifida.* Retrieved from cdc.gov/ncbddd/spinabifida/facts.html 2015

Centers for Disease Control and Prevention [CDC]. (2015). *BMI percentile calculator for child and teen*. Retrieved from https://nccd.cdc.gov/dnpabmi/Calculator.aspx

Chan, M., Miller, G. E., Chen, E., (2016). Early life socioeconomic status and metabolic outcomes in adolescents: The role of implicit affect about one's family. *Health Psychology, 35*(4), 387–396. doi: /10.1037/hea0000308

Chen, E., Fisher, E. B., Bacharier, L. B., & Strunk, R. C., (2003). Socioeconomic status, stress, and immune markers in adolescents with asthma. *Psychosomatic Medicine*, *65*(6), 984–992. doi: 10.1097/01.PSY.0000097340.54195.3C

Chen, E., Martin, A. D., & Matthews, K. A. (2006). Understanding health disparities: The role of race and socioeconomic status in children's health. *American Journal of Public Health, 96*(4), 702–708. doi: 10. .2105/AJPH.2004.048124

Chen, E., Matthews, K. A., & Boyce, W. T. (2002). Socioeconomic differences in children's health: How and why do these relationships change with age? *Psychological Bulletin, 128*(2), 295–329. doi: 0.1037//0033-2909.128.2.295

Chen, E., & Miller G. E. (2013). Socioeconomic status and health: Mediating and moderating factors. *Annual Review of Clinical Psychology, 9*, 723–749. doi: 10.1146/annurev-clinpsy-050212-185634.

Cheng, T. L., Goodman, E., & The Committee on Pediatric Research (2015). Race, ethnicity, and socioeconomic status in research on child health. *Pediatrics,* 135(1), e225–237, doi: 10.1542/peds.2014-3109

Cirino, P. T., Chin, C. E., Sevcki, R. A., Wolf, M., Lovett, M., & Morris, R. D. (2002). Measuring socioeconomic status: Reliability and preliminary validity for different approaches. *Assessment, 9*(2), 145–155. doi: 10.1177/10791102009002005

Coakley, R. M., Holmbeck, G. N., Friedman, D., Greenly, R. N., & Thill, A. W. (2002). A longitudinal study of pubertal timing, parent-child conflict, and cohesion in families of young adolescents with spina bifida. *Journal of Pediatric Psychology, 27*(5), 461–473. doi: 10.1093/jpepsy/27.5.461

Cohen, J. (1992). A power primer. *Quantitative Methods in Psychology, 112*(1), 155–159. doi: 10.1037/0033-2909.112.1.155

Coker, T. R., Elliot, M. N., Toomey, S. L., Schwebel, D. C., Cuccaro, P., Emery, S. T., … Schuster, M. A. (2016). Racial and ethnic disparities in ADHD Diagnosis and treatment. *Pediatrics, 138*(3), 85–93. Doi: 10.1542/peds.2012-2390

Conger, R. D., Conger, K. J., & Martin, M. J. (2010). Socioeconomic status, family processes, and individual development. *Journal of Marriage and Family*, *72*(3), 685–704. doi: 10.1111/j.1741-3737.2010.00725.x.

Conger, R. D., & Donnellan, M. B. (2007). An interactionist perspective on the socioeconomic context of human development. *Annual Review of Psychology, 58,* 175–199. doi: 10.1146/annurev.psych.58.110405.085551

Conger, R. D., & Elder, G. H. (1994). *Families in troubled times: Adapting to change in rural America*. Hawthorne, NY: Aldine de Gruyter.

Connor-Smith, J. K., Compas, B. E., Wadsworth, M. E., Thomsen, A. H., & Saltzman, H. (2000). Responses to stress in adolescence: Measurement of coping and involuntary stress responses. *Journal of Consulting and Clinical Psychology*, *68*(6), 976–992. doi:10.1037/0022-006X.68.6.976

Cope, H., McMahon, K., Heise, E., Eubanks, S., Garrett, M., Gregory, S., & Ashley-Koch, A. (2013). Outcome and life satisfaction of adults with myelomeningocele. *Disability and Health Journal*, *6*(3), 236–243. doi:10.1016/j.dhjo.2012.12.003

Copp, A. J., Adzick, N. S., Chitty, L. S., Fletcher, J. M., Holmbeck, G. N. & Shaw, G. M. (2015). Spina bifida. *Nature Review, Disease Primers*, *1*(15007), doi: 10.1038/nrdp.2015.7

Coscia, J. M., Christensen, B. K., Henry, R. R., Wallston, K., Radcliffe, J., & Rutstein, R., (2001). Effects of home environment, socioeconomic status, and health status on cognitive functioning in children with HIV-1 infection. *Journal of Pediatric Psychology*, *26*(6), 321–329. doi: 10.1093/jpepsy/26.6.321

Costigan, C. L., Floyd, F. J., Harter, K. S. M., & McClintock, J. C. (1997). Family process and adaptation to children with mental retardation: Disruption and resilience in family problem-solving interactions. *Journal of Family Psychology*, *11*(4), 515–529. doi: 10.1037/0893-3200.11.4.515

Crider, K. S., Zhu, J. H., Ling, H., Yang, T. P., Gindler, J., Maneval, D. R. … Berry, R. J. (2011). MTHFR 677CàT genotype is associated with folate and homocysteine concentrations in a large population-based, double blind trial of folic acid supplementation. *American Journal of Clinical Nutrition*, *93*(6), 1365–1372. doi:10.3945/ajcn.110.004671

Cundiff, J. M., Boylan J. M., Pardini, D. A., & Matthews K. A. (2017). Moving up matters: Socioeconomic mobility prospectively predicts better physically health. *Health*

Psychology, 36(6) 609–617. doi: 10.1037/hea0000473

Cunningham, S., Thomas, P., & Warschausky, S. (2007). Gender differences in peer relations of children with neurodevelopmental conditions. *Rehabilitation Psychology, 52*(3), 331–337. doi: 10.1037/0090-5550.52.3.331

Davis-Kean, P. E. (2005). The influence of parent education and family income on child achievement: The indirect role of parental expectations and the home environment. *Journal of Family Psychology, 19*(2), 294–304. doi: 10.1037/0893-3200.19.2.294

De Civita, M., Regier, D., Alamgir, A. H., Anis, A. H., FitzGerald, M. J., & Marra, C. A. (2005). Evaluating health-related quality-of-life studies in paediatric populations: Some conceptual, methodological and developmental considerations and recent applications. *Pharmacoeconomics, 23*(7), 659–685. doi: 10.2165/00019053-200523070-00003

De Jong, T. P. V. M., Chrzan, R., Klin, A. J., & Dik, P. (2008). Treatment of neurogenic bladder in spina bifida. *Pediatric Nephrology, 23,* 889–896. doi: 10.1007/s00467-008-0780-7

Dennis, M., Landry, S. H., Barnes, M., & Fletcher, J. M. (2006). A model of neurocognitive function in spina bifida over the life span. *Journal of the International Neuropsychological Society, 12*(2), 285–296. doi: 10.1017/S1355617706060371

Devine, K. A., Holbein, C. E., Psihogios, A. M., Amaro, C. M., & Holmbeck, G. N. (2012). Individual adjustment, parental functioning, and perceived social support in Hispanic and non-Hispanic white mothers and fathers of children with spina bifida. *Journal of Pediatric Psychology, 37*(7), 769–778. doi:10.1093/jpepsy/jsr083

Diemer, M. A., Mistry, R. S., Wadsworth, M. E., Lopez, I., & Reimers, F. (2013). Best practices in conceptualizing and measuring social class in psychological research. *Analyses of Social Issues and Public Policy, 13*(1), 77–113. doi: 10.1111/asap.12001

Doan, S. N., Fuller-Rowell, T. E., Evans, G. W. (2012). Cumulative risk and adolescent's internalizing and externalizing problems: the mediating roles of maternal responsiveness and self-regulation. *Developmental Psychology, 48*(6), 1529–1539. doi: 10.1037/a0027815

Drew, L. M., Berg, C., King, P., Verdant, C., Griffith, K., Butler, J., & Wiebe, D. J. (2011). Depleted parental psychological resources as mediators of the association of income with adherence and metabolic control. *Journal of Family Psychology, 25*(5), 751–758. doi: 10.1037/a0025259.

Duncan, G. J., & Magnuson, K., (2001). Off with Hollingshead: Socioeconomic resources, parenting, and child development. In M. Bornstein and R. Bradley (Eds.) *Socioeconomic status, parenting, and child development* (pp.83–106). Mahwah, NJ: Lawrence Erlbaum.

Eiser, C., & Jenney, M. (2007). Measuring quality of life. *Archives of Disease in Childhood, 92*(4), 348–350. doi: 10.1136/adc.2005.086405

Ellerton, M. L., Stewart, M. J., Ritchie, J. A., & Hirth, A.M. (1996). Social support in children with a chronic condition. *Canadian Journal of Nursing Research, 28*(4), 15–36.

Essner, B. S. & Holmbeck, G. N. (2010). The impact of family, peer, and social contexts on depressive symptoms in adolescents with spina bifida. *Rehabilitation Psychology, 55*(4), 340–350. doi: 10.1037/a0021664

Essner, B. S., Murray, C. B., & Holmbeck, G. N. (2014). The influence of condition parameters and internalizing symptoms on social outcomes in youth with spina bifida. *Journal of Pediatric Psychology*, 39(7), 718–734. doi*:* 0.1093/jpepsy/jsu036

Evans, G. W. (2003). A multimethod analysis of cumulative risk and allostatic load among rural children. *Developmental Psychology, 39*(5), 924–933. doi: 10.1037/0012-1649.39.5.924

Evans, G. W. (2004). The environment of childhood poverty. *American Psychologist, 59*(2), 77–92. doi: 10.1037/0003-066X.59.2.77

Evans, G. W., & Kim, P. (2007). Childhood poverty and health: Cumulative risk exposure and stress dysregulation. *Psychological Science, 18*(11), 953–957. doi: 10.1111/j.1467-9280.2007.02008.x

Evans, G. W., Kim, P., Ting, A. H., Tesher, H. B., & Shannis, D. (2007). Cumulative risk, maternal responsiveness, and allostatic load among young adolescents. *Developmental Psychology, 43*(2), 341–351. doi: 10.1037/0012-1649.43.2.341

Fletcher, J. M., & Brei, T. J. (2010). Introduction: Spina bifida–A multidisciplinary perspective. *Developmental Disabilities Research Reviews, 16*(1), 1–5. doi: 10.1002/ddrr.101

Fletcher, J. M., Copeland, K., Frederick, J. A., Blaser, S. E., Kramer, L. A., Northrup, H., … Dennis, M. (2005). Spinal lesion level in spina bifida: A source of neural and cognitive heterogeneity. *Journal of Neurosurgery, 102*(3), 268–279. doi: 10.3171/ped.2005.102.3.0268

Fradkin, C., Wallander, J. L., Elliot, M. N., Tortolero, S., Cuccaro, P., & Schuster, M. A., (2015). Associations between socioeconomic status and obesity in diverse, young adolescents:

Variation across race/ethnicity and gender. *Health Psychology, 34*(1), 2014, 1–9. doi: 10.1037/hea0000099

Franks, P., Tancredi, D. J., Winter, P., & Fiscella, K. (2010) Including socioeconomic status in coronary heart disease risk estimation. *Annals of Family Medicine, 8*(5), 447–453. doi: 10.1370/afm.1167

Frederick, C. B., Snellman, K., & Putnam, R. D. (2014). Increasing socioeconomic disparities in adolescent obesity. *Proceedings of the National Academy of Sciences of the United States of America [PNAS], 11*(4), 1339–1342. doi: 10.1073/pnas.1321355110

Friedman D., Holmbeck, G. N., Jandasek, B., Zukerman, J., & Abad, M. (2004). Parent functioning in families of preadolescents with spina bifida: Longitudinal implications for child adjustment. *Journal of Family Psychology, 18*(4), 609–619. doi: 10.1037/0893-3200.18.4.609

Fritz, M. S., & MacKinnon, D. P. (2007). Required sample size to detect the mediated effect. *Psychological Science, 18*(3), 233–239. doi:10.1111/j.1467-9280.2007.01882.x.

Geronimus, A. T., Hicken, M., Keene, D., & Bound. J. (2006). “Weathering” and age patterns of allostatic load scores among blacks and whites in the United States. *American Journal of Public Health, 96*(5), 826–833. doi: 10.2105/AJPH.2004.060749

Getahum, D., Jacobsen, S. J., Fassett, M. J., Chen, W., Demissie, K., & Rhoads, G. G. (2013). Recent trends in childhood Attention-Deficit/Hyperactivity Disorder. *Journal of the American Medical Association Pediatrics, 167*(3), 282–288. doi: 10.1001/2013.jamapediatrics.401

Gioia, G. A., Isquith, P.K., Guy, S. C., & Kenworthy, L. (2000). *BRIEF: Behavior Rating Inventory of Executive Function: Professional manual.* Odessa, FL: Psychological Assessment Resources, Inc.

Gortmaker, S. L, Sappenfield, W. (1984). Chronic childhood disorders: prevalence and impact. *Pediatrics Clinics of North America, 31*(1), 3–18. doi: 10.2105/AJPH.82.3.364

Graber, J. A. (2004). Internalizing problems during adolescence. In R. M. Lerner & L. Steinberg (Eds.), *Handbook of adolescent psychology* (2nd ed., pp. 587–626). Hoboken, NJ: John Wiley & Sons, Inc.

Grewal, J., Carmichael, S. L., Song, J., & Shaw, G. M., (2009). Neural tube defects: an analysis of neighbourhood- and individual-level socio-economic characteristics. *Paediatric Perinatal Epidemiology, 23*(2), 116–124. doi:10.1111/j.1365-3016.2008.00992.x.

Guerra, N. G., & Leidy, M. (2008). Lessons learned: Recent advances in the prevention and treatment of childhood aggression. In R. Kail (Ed.), *Advances in child development and behavior*, (Vol. 36, pp. 287–330). Boston, MA: Elsevier.

Harter, S. (1985). *Manual for Self-Perception Profile for Children: Revision of the Perceived Competence Scale for Children*. Denver, CO: University of Denver.

Hayes, A. F. (2009). Beyond Baron and Kenny: Statistical mediation analysis in the new millennium. *Communication Monographs, 76*(4), 408–420. doi: 10.1080/03637750903310360

Hayes, A. F. (2013). *Introduction to mediation, moderation, and conditional process analysis: A regression-based approach.* New York, NY: Guilford Press

Herman, J. P. (2013). Neural control of chronic stress adaptation. *Frontiers in Behavioral Neuroscience, 7*(61), 1–12. doi: 10.3389/fnbeh.2013.00061

Hetherington, R., Dennis, M., Barnes, M., Drake, J., & Gentili, F. (2005). Functional outcome in young adults with spina bifida and hydrocephalus. *Children's Nervous System, 22*(2), 117–124. doi:10.1007/s00381-005-1231-4

Holbein, C. E., Murray, C. B., Psihogios, A. M., Wasserman, R. M., Essner, B., & Holmbeck, G. N. (2013). A camp-based psychosocial intervention to promote independence and social function in individuals with spina bifida: Moderators of treatment effectiveness. *Journal of Pediatric Psychology 38*(4), 412–424. doi:10.1093/jpepsy/jst003

Holbein, C. E., Lennon, J. M., Kolbuck, V. D., Zebracki, K., Roache, C., & Holmbeck, G. N. (2015). Observed differences in social behaviors exhibited in peer interactions between youth with spina bifida and their peers: Neuropsychological correlates. *Journal of Pediatric Psychology, 40*(3), 320–335. doi: 10.1093/jpepsy/jsu101

Holbein, C. E., Zebracki, K., Bechtel, C. F., Papadakis, J. L., Bruno, E. F., & Holmbeck, G. N. (2017). Milestone achievement in emerging adulthood in spina bifida: a longitudinal investigation of parental expectations. *Developmental Medicine & Child Neurology, 59*(3), 311–316. doi: 10.1111/dmcn.13279.

Hollingshead, A. B. (1975). *Four Factor Index of Social Status*. New Haven, CT: Yale University.

Holmbeck, G. N. (1997). Toward terminological, conceptual, and statistical clarity in the study of mediators and moderators: Examples from the child-clinical and pediatric psychology literatures. *Journal of Consulting and Clinical Psychology, 65*(4), 599–610. doi: 10.1037/0022-006X.65.4.599

Holmbeck, G. N. (2002). Post-hoc probing of significant moderational and mediational effects in studies of pediatric populations. *Journal of Pediatric Psychology, 27*(1), 87–96. doi: 10.1093/jpepsy/27.1.87

Holmbeck, G. N., Coakley, R. M., Hommeyer, J., Shapera, W. E., & Westhoven, V. (2002). Observed and perceived dyadic and systemic functioning in families of preadolescents with spina bifida. *Journal of Pediatric Psychology, 27*(2), 177–189. doi: 10.1093/jpepsy/27.2.177

Holmbeck, G. N., DeLucia, C., Essner, B., Kelly, L., Zebracki, K., Friedman, D., & Jandasek, B. (2010). Trajectories of psychosocial adjustment in adolescents with spina bifida: A 6-Year, four-wave longitudinal follow-up. *Journal of Consulting and Clinical Psychology, 78*(4), 511–525. doi: 10.1037/a0019599

Holmbeck, G. N., & Devine, K. A. (2010). Psychological and family functioning in spina bifida. *Developmental Disabilities, 16*(1), 40–46. doi: 10.1002/ddrr.90

Holmbeck, G. N., Greenley, R. N., Coakley, R. M., Greco, J., & Hagstrom, J. (2006). Family functioning in children and adolescents with spina bifida: An evidence-based review of research and interventions. *Journal of Developmental and Behavioral Pediatrics, 27*(3), 249–277. doi: 10.1097/00004703-200606000-00012

Holmbeck, G. N., Johnson, S. Z., Wills, K., McKernon, W., Rolewick, S., & Skubic, T. (2002). Observed and perceived parental overprotection in relation to psychosocial adjustment in pre-adolescents with a physical disability: The mediational role of behavioral autonomy. *Journal of Consulting and Clinical Psychology, 70*(1), 96–110. doi: 10.1037/0022-006X.70.1.96

Holmbeck, G. N., Westhoven, V. C., Phillips, W. S., Bowers, R., Gruse, C., Nikolopoulos, T., Tortura, C. M., & Davison, K. (2003). A multimethod, multi-informant, and multidimensional perspective on psychosocial adjustment in preadolescents with spina bifida. *Journal of Consulting and Clinical Psychology, 71*(4), 782–796. doi: 10.1037/0022-006X.71.4.782

Holmbeck, G. N., Zebracki, K., Papadakis, J. L., & Driscoll, C. F. B. (2017). Spina bifida. In M. C. Roberts & R. G. Steele (Eds.), *Handbook of pediatric psychology* (5th ed.; pp.312–322). New York, NY: Guilford Press.

Husmann, D. A. (2009). Malignancy after gastrointestinal augmentation in childhood. *Therapeutic Advances in Urology, 1*(1), 5–11. doi: 10.1177/1756287209104163

Jandasek, B., Holmbeck, G. N., DeLucia, C., Zebracki, K., & Friedman, D. (2009). Trajectories of family processes across the adolescent transition in youth with spina bifida. *Journal of Family Psychology, 23*(5), 726–738. doi: 10.1037/a0016116

Johnson, K. L., Dudgeon, B., Kuehn, C., & Walker, W. (2007). Assistive technology use among adolescents and young adults with spina bifida. *American Journal of Public Health, 97*(2), 330–336. doi: 10.2105/AJPH.2004.050955

Jones, D. J., Forehand, R., Brody, G., & Armistad, L. (2002). Psychosocial adjustment of African American children in single-mother families: A test of three risk model. *Journal of Marriage and Family, 64*(1), 105–115. doi: 10.1111/j.1741-3737.2002.00105.x

Judd, L. L., Paulus, M. J., Schettler, P. J., Akiskal, H. S., Endicott, J., Leon, A. C, … Keller, M. B. (2000). Does incomplete recovery from first lifetime major depressive episode herald a chronic course of illness? *American Journal of Psychiatry, 157*(9), 1501–1504. doi: 10.1176/appi.ajp.157.9.1501

Kabra, A. T., Feustal, P. J., & Kogan, B. A. (2015) Screening for depression and anxiety in childhood neurogenic bladder dysfunction. *Journal of Pediatric Urology, 11*(2), 75.e1-75.e7. doi: 10.1016/j.jpurol.2014.11.017

Kelly, N. C., Ammerman, R. T., Rausch, J. R., Ris, M. D., Yeates, K. O., Oppenheimer, S.G., & Enrile, B. G. (2012). Executive functioning and psychological adjustment in children and youth with spina bifida. *Child Neuropsychology, 18*(5), 417–431. doi: 10.1080/09297049.2011.613814

Kim J., & Cicchetti, D. (2004). A longitudinal study of child maltreatment, mother-child relationship quality and maladjustment: The role of self-esteem and social competence. *Journal of Abnormal Child Psychology, 32*(4), 341–354. doi: 10.1023/B:JACP.0000030289.17006.5a

King, S., Chambers, C. T., Huguet, A., MacNevin, R. C., McGrath, P. J., Parker, L. J., & MacDonald, A. J. (2011). The epidemiology of chronic pain in children and adolescents revisited: A systematic review. *Pain, 152*(12), 2729-2738. doi: 10.1016/j.pain.2011.07.016

Klepper, S. (1999). Effects of an eight-week physical conditioning program on disease signs and symptoms in children with chronic arthritis. *Arthritis Care and Research, 12*(1), 52–60. doi: 10.1002/1529-0131(199902)12:1<52::AID-ART9>3.0.CO;2-X

Kovacs, M. (1992). *Children's Depression Inventory—Manual.* North Tonawanda, NY: Multi-Health Systems.

Kulkarni, A. V., Cochrane, D. D., McNeely, P. D., & Shams, I. (2008). Medical, social, and economic factors associated with health-related quality of life in Canadian children with hydrocephalus. *The Journal of Pediatrics, 153*(5), 689–695. doi: 10.1016/j.jpeds.2008.04.068

Lavigne, J. V., & Faier-Routman, J. (1992). Psychological adjustment to pediatric physical disorders: A meta- analytic review. *Journal of Pediatric Psychology, 17*(2), 133–157. doi: 10.1093/jpepsy/17.2.133

Law, M., King, G., King, S., Kertoy, M., Hurley, P., Rosenbaum, P., … Hanna, S. (2006). Patterns of participation in recreational and leisure activities among children with complex physical disabilities. *Developmental Medicine & Child Neurology, 48*(5), 337–342. doi: 10.1017/S0012162206000740

Lennon, J. M., Klages, K. L., Amaro, C. M., Murray, C. B., & Holmbeck, G. N. (2015). Longitudinal study of neuropsychological functioning and internalizing symptoms in youth with spina bifida: Social competence as a mediator. *Journal of Pediatric Psychology, 40*(3), 336–348. doi: 10.1093/jpepsy/jsu075.

Lescano, C. M., Koinis-Mitchell, D., McQuaid, E. L. (2016). Introduction to the special issue on diversity and health disparities: Where have we been and where are we going? *Journal of Pediatric Psychology, 41*(4), 385–390, doi: 10.1093/jpepsy/jsw020

Liptak, G. S., Garver, K., & Dosa, N. (2013). Spina bifida grown up. *Journal of Developmental & Behavioral Pediatrics, 34*(3), 206–215. doi: 10.1111/j.1464-410X.2005.05374.x

Liptak, G. S., Kennedy, J. A., & Dosa, N. P. (2010). Youth with spina bifida and transitions: Health and social participation in a nationally represented sample. *The Journal of Pediatrics, 157*(4), 584–588. doi: 10.1016/j.jpeds.2010.04.004

Liptak, G. S., Robinson, L. M., Davidson, P. W., Dziorny, A., Lavalley, R., Flaherty, M. G., & Dosa, N. P. (2015). Life course health and healthcare utilization among adults with spina bifida. *Developmental Medicine & Child Neurology, 58*(7), 714–720. doi: 10.1111/dmcn.12952

Little, R. J. A. (1988). A test of missing completely at random for multivariate data with missing values. *Journal of the American Statistical Association, 83*(404). 1198–1202. doi: 10.1080/01621459.1988.10478722

Lomax-Bream, L. E., Barnes, M., Copeland, K., Taylor, H. B., & Landry, S. H. (2007). The impact of spina bifida on development across the first 3 years. *Developmental Neuropsychology, 31*(1), 1–20. doi: 10.1080/87565640709336884

Lord, J. H., Young, M. T., Gruhn, M., Grey, M., Delameter, A., & Jaser, S. S. (2015). Effect of race and marital status on mothers' observed parenting and adolescent adjustment in youth with type 1 diabetes. *Journal of Pediatric Psychology, 40*(1), 132–143. doi: 10.1093/jpepsy/jsu078

MacKinnon, D. P., Warsi, G., & Dwyer, J. H. (1995). A simulation study of mediated effect measures. *Multivariate Behavioral Research, 30*(3), 41–62. doi: 10.1207/s15327906mbr3001_3

Martel, M. M. (2013). Individual differences in attention deficit hyperactivity disorder symptoms and associated executive dysfunction and traits: Sex, ethnicity, and family income. *American Journal of Orthopsychiatry, 83*(203), 165–175. doi:10.1111/ajop.12034.

McPherson, A. C., Swift, J. A., Yung, E., & Church, P. (2013). The assessment of weight status in children and young people attending a spina bifida outpatient clinic: a retrospective medical record review. *Disability and Rehabilitation, 35*(25) 2123–2131. doi: 10.3109/09638288.2013.771705

Miranda, A., Colomer, C., Mercader, J., Fernandez, M. I., & Presentacion, M. J. (2015). Performance-based tests versus behavioral ratings in the assessment of executive functioning in preschoolers: associations with ADHD symptoms and reading achievement. *Frontiers in Psychology, 6*(545), 1–10. doi: 10.3389/fpsyg.2015.00545

Mullins, L. L., Wolfe-Christensen, C., Chaney, J. M., Elkin, T. D., Wiener, L., Hullmann, S. E., Fedele, D. A., Junghans, A. (2011). The relationship between single-parent status and parenting capacities in mothers of youth with chronic health conditions: the mediating role of income. *Journal of Pediatric Psychology, 36*(3), 249–257. doi: 10.1093/jpepsy/jsq080

Murray, C. B., Holmbeck, G. N. Ros, A. M., Flores, D. M., Mir, S. A., & Varni, J. W. (2015). A longitudinal examination of health-related quality of life in children and adolescents with spina bifida. *Journal of Pediatric Psychology, 40*(4), 419–430. doi: 10.1093/jpepsy/jsu098.

Murray, C. B., Kirsch, A. C., Palermo, T. M., Holmbeck, G. N., Kolbuck, V., Psihogios, A., & Pigott, T. (2016). Developmental course and determinants of sleep disturbances in adolescents with spina bifida. *Journal of Pediatric Psychology, 41*(6), 631–642. doi: 10.1093/jpepsy/jsw021

National Birth Defects Prevention Network [NBDPN] (2010). *Prevalence of spina bifida and anencephalybefore and after folic acid fortification.* Retrieved from http://www.nbdpn.org/current/2010pdf/NTD%20fact%20sheet%2001-10%20for%20website.pdf

Oakeshott, P., Hunt, G. M., Poulton, A. & Reid, F., (2010). Expectation of life and unexpected death in open spina bifida: A 40-year complete, non-selective, longitudinal cohort study. *Developmental Medicine & Child Neurology, 52*(8), 749–753. doi: 10.1111/j.1469-8749.2009.03543.x.

Okurowska-Zawada, B., Kulak, W., Otapowicz, D., Sienkiewicz, D., Paszko-Patej, G., & Wojtkowski, J. (2011). Quality of life in children and adolescents with cerebral palsy and myelomeningocele. *Pediatric Neurology, 45*(3), 163–168. doi: 10.1016/j.pediatrneurol.2011.04.006

Ouyang, L. J, Grosse, S. D, Armour, B. S., Waitzman, N. J. (2007). Health care expenditures of children and adults with spina bifida in a privately insured US population. *Birth Defects Research Part A Clinical and Molecular Teratology, 79*(7), 552–558. doi: 10.1002/bdra.20360

Palermo, T. M., Zebracki, K., Newman, A., & Singer, N. (2004). Juvenile idiopathic arthritis: Parent-child discrepancy on reports of pain and disability. *Journal of Rheumatology, 31*(9), 1840–1846. doi: 10.1.1.852.6487

Palisano, R., Rosenbaum, P., Walter, S., Russell, D., Wood, E., & Galuppi, B. (1997). Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Developmental Medicine and Child Neurology, 39*(4), 214–223. doi: 10.1111/j.1469-8749.1997.tb07414.x

Papadakis, J. L., Acevedo, L., Ramirez, S., Stern, A., Driscoll, C. F. B., & Holmbeck, G. N. (2018). Psychosocial and family functioning among Latino youth with spina bifida. *Journal of Pediatric Psychology, 43*(2), 105–119. doi: 10.1093/jpepsy/jsx096.

Parekh, A. D., Trusler, L. A., Pietsch, J. B., Byrne, D. W., DeMarco, R. T., Pope, J. C. IV, . . . Brock, J. W. III (2006). Prospective, longitudinal evaluation of health related quality of life in the pediatric spina bifida population undergoing reconstructive urological surgery. *The Journal of Urology, 176*(4 part 2), 1878–1882. doi: 10.1016/S0022-5347(06)00620-3

Parker, S. E., Mai C. T., Canfield, M. A., Rickard, R., Wang, Y., Meyer, R. E, …& The National Birth Defects Prevention Network (2010). Updated national birth prevalence estimates for selected birth defects in the United States, 2004-2006. *Birth Defects Research Part A Clinical and Molecular Teratology, 88*(12), 1008–1016. doi: 10.1002/bdra.20735

Pastor, P. N., Reuben, C. A., Duran, C. R., & Hawkins, L. D. (2015). Association between diagnosed ADHD and selected characteristics among children aged 4-17 years: United States, 2011-2013. *National Center for Health Statistics Data Brief, no. 201*. Hyattsville, MD: National Center for Health Statistics. 2015.

Pickett, K. E., & Pearl, M. (2001). Multilevel analyses of neighbourhood socioeconomic context and health outcomes: A critical review. *Journal of Epidemiology and Community Health, 55*(2), 111–122. doi: 10.1136/jech.55.2.111

Pless, C. E., & Pless, I. B. (1995). How well the remember: The accuracy of parent reports. *Archives of Pediatric Adolescent Medicine, 149*(5), 553–558. doi: 10.1001/archpedi.1995.02170180083016

Poleshuck, E. L., & Green, C. R. (2008). Socioeconomic disadvantage and pain. *Pain, 136*(3), 235–238. doi: 10.1016/j.pain.2008.04.003

Preacher, K. J., & Hayes, A. F. (2008). Asymptotic and resampling strategies for assessing and comparing indirect effects in multiple mediator models. *Behavior Research Methods, 40*(3), 879–891.doi: 10.3758/BRM.40.3.879

Psihogios, A. M., Kolbuck, V., & Holmbeck, G. N. (2015). Condition self-management in pediatric spina bifida: A longitudinal investigation of medical adherence, responsibility-sharing, and independence skills. *Journal of Pediatric Psychology, 40*(8), 790–803. doi: 10.1093/jpepsy/jsv044

Quittner, A. L., Glueckauf, R. L., & Jackson, D. N. (1990). Chronic parenting stress: Moderating versus mediating effects of social support. *Journal of Personality and Social Psychology, 59*(6), 1266–1278. doi: 10.1037/0022-3514.59.6.1266

Riddle, R., Morton, A., Sampson, J. D., Vachha, B., & Adams, R. (2005). Performance on the NEPSY among children with spina bifida. *Archives of Clinical Neuropsychology, 20*(2), 243–248. doi: 10.1016/j.acn.2004.07.004

Rofail, D., Macguire, L., Kissner, M., Colligs, A., & Abetz-Webb, L. (2013). A review of the social, psychological, and economic burdens experienced by people with spina bifida and their caregivers. *Neurology & Therapy, 2*(1-2), 1-12. doi: 10.1007/s40120-013-0007-0

Rose, B. M., & Holmbeck, G. N. (2007). Attention and executive functions in adolescents with spina bifida. *Journal of Pediatric Psychology, 32*(8), 983–994. doi: 10.1093/jpepsy/jsm042

Rubin, K. H., Chen, X., McDougall, P., Bowker, A., McKinnon, .J (1995). The Waterloo Longitudinal Project: Predicting internalizing and externalizing problems in adolescence. *Developmental Psychopathology, 7*(4), 751–764. doi: 10.1017/S0954579400006829

Rutter, M. (1983). Statistical and personal interactions: Facets and perspectives. In D. Magnusson & V. Allen (Eds.), *Human development: An interactional perspective* (pp. 295–319). New York, NY: Academic Press.

Rutter, M. (1993). Stress, coping, and development. In N. Garmezy & M. Rutter (Eds.), *Stress, coping, and development* (pp. 1–41). New York, NY: McGraw-Hill.

Sandler, A. (2004). *Living with spina bifida: A guide for families and professionals*. Chapel Hill, NC: The University of North Carolina Press.

Sameroff, A. J. (2000). Developmental systems and psychopathology. *Developmental Psychopathology, 12*(3), 297–312. doi: 10.1017/S0954579400003035

Sameroff, A. J., Seifer, R., & McDonough, S. C. (2004). Contextual contributors to the assessment of infant mental health. In R. DelCarmen-Wiggins & A. Carter (Eds.) *Handbook of infant, toddler, and preschool mental health assessment* (pp. 61–76). New York, NY: Oxford University Press.

Santiago, C. D., & Wadsworth, M. E. (2009). Coping with family conflict: What's helpful and what's not for low-income adolescents. *Journal of Child and Family Studies, 18*(2), 192-202. doi:10.1007/s10826-008-9219-9

Sawin, K. J., & Bellin, M. H. (2010). Quality of life in individuals with spina bifida: A research update. *Developmental Disabilities Research Reviews, 16*(1), 47–59. doi: 10.1002/ddrr.96

Schafer, J. L., & Graham, J. W. (2002). Missing data: Our view of the state of the art. *Psychological Methods, 7*(2), 147–177. doi: 10.1037//1082-989X.7.2.147

Schechter, M. S., Liu, T., Soe, M., Swanson, M., Ward, E., & Thibadeau, J. (2015). Sociodemographic attributes and spina bifida outcomes. *Pediatrics, 135*(4), 957–964. doi: 10.1542/peds.2014-2576

Schwarz, J. N., Monti, A., Savelli-Castillo, L., Nelson, N. P. (2004). Accuracy of familial reporting of a child's medical history in a dental clinic setting. *Pediatric Dentistry, 26*(5), 433–439.

Shavers, V. L. (2007) Measurement of socioeconomic status in health disparities research. *Journal of The National Medical Association, 99*(9), 1013–1023.

Shields, N., Taylor, N. F., & Dodd, K. J. (2008). Self-concept in children with spina bifida compared with typically developing children. *Developmental Medicine & Child Neurology, 50*(10), 733–743. doi: 10.1111/j.1469-8749.2008.03096.x

Shin, M., Besser, L. M., Siffel, C., Kucik, J. E., Shaw, G. M., Lu, C., . . . Congenital Anomaly Multistate Prevalence and Survival Collaborative. (2010). Prevalence of spina bifida among children and adolescents in 10 regions in the United States. *Pediatrics, 126*(2), 274–279. doi: 10.1542/peds.2009-2084

Shonk, S. M., Cicchetti, D. (2001). Maltreatment, competency deficits, and risk for academic and behavioral maladjustment. *Developmental Psychology, 37*(1), 3–17. doi: 10.1037/0012-1649.37.1.3

Slavin, L.A. (1991). Validation studies of the PEPSS, a measure of perceived emotional support for use with adolescents. *Journal of Adolescent Research, 6*(3), 316–335. doi: 10.1177/074355489163004

Sobel, M. E. (1982). Asymptotic confidence intervals for indirect effects in structural equation models. In S. Leinhardt (Ed.), *Sociological Methodology* (pp. 290–312). Washington, DC: American Sociological Association.

Spina Bifida Association (2008). *Spina Bifida.* Retrieved from www.spinabifidaassociation.org

Swanson, J. M., Kraemer, H. C., Hinshaw, S. P., Arnold, L. E., Conners, C. K., Abikoff, H. B., … Wu, M. (2001). Clinical relevance of the primary findings of the MTA: Success rates based on severity of ADHD and ODD symptoms at the end of treatment. *Journal of the American Academy of Child and Adolescent Psychiatry, 40*(2),168–179. doi:10.1097/00004583-200102000-00011

Swartwout, M. D., Garnaat, S. L., Myszka, K. A., Fletcher, J. M., & Dennis, M. (2010). Associations of ethnicity and SES with IQ and achievement in spina bifida meningomyelocele. *Journal of Pediatric Psychology, 35*(9), 927–936. doi: 10.1093/jpepsy/jsq001

Tabachnick, B. G., & Fidell, L. S. (2013) *Using multivariate statistics* (6th ed.) Upper Saddle River, NJ: Pearson Education.

Tilford, J. M., Grosse, S. D., Goodman, A. C., & Li, K. (2009). Labor market productivity costs for caregivers of children with spina bifida: A population-based analysis. *Medical Decision Making, 29*(1), 23–32. doi: 10.1177/0272989X08322014

Tinker, S. C., Hamner, H., Crider, & K. S. (2014). Red blood cell folate concentrations among non-pregnant United States women of childbearing age, National Health and Nutrition Examination Survey, 2007–2010. *Abstract presented at 47th Annual Meeting of the Society for Epidemiologic Research, June 24-27, 2014, Seattle, WA*. Retrieved from http://epiresearch.org/wp-content/uploads/2014/08/abstract-book-printed.pdf

Trentacosta, C. J., Hyde, L. W., Shaw, D. S., Dishion, T. J., Gardner, F., & Wilson, M. (2008). The relations among cumulative risk, parenting, and behavior problems during early childhood. *Journal of Child Psychology and Psychiatry, 49*(11), 1211–1219. doi: 10.1111/j.1469-7610.2008.01941.x

Tuminello, E. R., Holmbeck, G. N., & Olson, R. (2012). Executive functions in adolescents with spina bifida: relations with autonomy development and parental intrusiveness. *Child Neuropsychology, 18*(2), 105–124. doi: 10.1080/09297049.2011.590470.

U.S. Census Bureau [USCB]. (2010). American Community Survey, data release. Retrieved from https://www.census.gov/programs-surveys/acs/news/data-releases.

U.S. Department of Health and Human Services [USDHHS]. (2001). *Mental Health: Culture, Race, and Ethnicity—A Supplement to Mental Health: A Report of the Surgeon General*. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services.

U.S. Department of Health and Human Services [USDHHS] (2009). The 2009 HHS poverty guidelines. Retrieved from https://aspe.hhs.gov/2009-hhs-poverty-guidelines

U.S. Food & Drug Administration [USFDA]. (2016). FDA approves folic acid fortification of corn masa flour. Retrieved from: http://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm496104.htm

Varni, J. W., Seid, M., & Kurtin, P. S. (2001). PedsQL 4.0: Reliability and validity of the pediatric quality of life inventory version 4.0 generic core scales in healthy and patient populations. *Medical Care, 39*(8), 800–812.

Velie, E. M., Shaw, G. M., Malcoe, L. H., Schaffer, D. M., Samuels, S. J., Todoroff, K., & Block, G. (2006). Understanding the increased risk of neural tube defect-affected pregnancies among Mexico-born women in California: immigration and anthropometric factors. *Paediatric Perinatal Epidemiology, 20*(3), 219–230 doi: 10.1111/j.1365-3016.2006.00722.x

Wechsler, D. (1999). *WASI: Wechsler Abbreviated Scale of Intelligence Manual*. San Antonio, Texas: Harcourt Assessment, Inc.

Wheeler, V. A. & Ladd, G. W. (1982). Assessment of children’s self-efficacy for social interactions with peers. *Developmental Psychology, 18*(6), 795–805. doi:10.1037/0012-1649.18.6.795

Wilkinson, G.S. (1993). *WRAT3: Wide Range Achievement Test Administration Manual*. Wilmington, DE: Wide Range, Inc.

Williams, J., Mai, C. T., Mulinare, J., Isenburg, J., Flood, T., Ethen, M., . . . Kirby, R. (2015). Updated estimates of neural tube defects precented by mandatory folic acid fortification-United States, 1995-2011. *MMWR Morbidity and Mortality Weekly Report, 64*(1), 1–5. Retrieved from https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6401a2.htm

Williams, L. J., Rasmussen, S. A., Flores, A., Kirby, R., & Edmonds, L. D. (2005). Decline in the prevalence of spina bifida and anencephaly by race/ethnicity: 1995-2002. *Pediatrics, 116*(3), 580–586. doi: 10.1542/peds.2005-0592

Wills, K. E. (1993). Neuropsychological functions in children with spina bifida and/on hydrocephalus. *Journal of Clinical Child Psychology, 22*(2), 247–265. doi: 10.1207/s15374424jccp2202_11

Wilson, S., Washington, L. A., Engel, J. M., Ciol, M. A., & Jensen, M. P. (2006). Perceived social support, psychological adjustment, and functional ability in youths with physical disabilities. *Rehabilitation Psychology, 51*(4), 322–330. doi: 10.1037/0090-5550.51.4.322

Wohlfeiler, M. W., Macias, M. M., & Saylor, C. F. (2008). Paternal correlates of cognitive and behavioral functioning in children with myelomeningocele. *Developmental Medicine & Child Neurology, 50,* 864–869. doi: 10.1111/j.1469-8749.2008.03070.x

Wysocki, T., & Gavin, L. (2006). Paternal involvement in the management of pediatric chronic diseases: Associations with adherence, quality of life, and health status. *Journal of Pediatric Psychology, 31*(5), 501–511. doi: 10.1093/jpepsy/jsj042

Yang, J., Carmichael, S. L., Canfield, M., Song, J., Shaw, G. M., & the National Birth Defects

Prevention Study. (2008) Socioeconomic status in relation to selected birth defects in a large multicentered US case-control study. *American Journal of Epidemiology, 167*(2), 145–154. doi: 10.1093/aje/kwm283

Yi, Y., Lindermann, M., Colligs, A., & Snowball, C. (2011). Economic burden of neural tube defects and impact of prevention with folic acid: a literature review. *European Journal of Pediatrics*, *170*(11), 1391–1400. doi: 10.1007/s00431-011-1492-8.

Zukerman, J. M., Devine, K. A., & Holmbeck, G. N. (2011). Adolescent predictors of emerging adulthood milestones in youth with spina bifida. *Journal of Pediatric Psychology, 36*(3), 265–276. doi: 10.1093/jpepsy/jsq075

VITA

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